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Speakers' contributions

DISABILITY-RELATED FINANCIAL INSTRUMENTS IN LIGHT OF EU LAW AND THE UNCRPD

SEMINAR FOR NATIONAL CIVIL SERVANTS, STAFF OF NGOs, DPOs AND EQUALITY BODIES

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In cooperation with the European Foundations Centre (EFC) and the European Disability Forum (EDF), and with the support of the European Commission (Contracting Authority).

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Presentation by

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coomara pyaneandee- vice-chairperson UNCRPD

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Overview of the presentation

1. Disability rights in the European Union
2. The European Charter of Fundamental Rights and disability
3. The United Convention on the Rights of Persons with Disabilities (UNCRPD) as part of the EU legal order
4. Secondary EU legislation protecting the rights of persons with disabilities
5. Issues of primacy, direct and indirect effect

1. Disability rights in the European Union treaties

- The European Union legal system is structured and hierarchical. Therefore, the starting point for considering the legal framework protecting disability rights within the European Union are the two core functional treaties, namely the Treaty on European Union (TEU), originally signed in Maastricht in 1992, and the Treaty on the Functioning of the European Union (TFEU) ,originally signed in Rome in 1957.

- The protection of human rights is firmly embedded in the TEU :
  - Article 2 TEU, states that “The Union is founded on the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minorities. These values are common to the Member States in a society in which pluralism, non-discrimination, tolerance, justice, solidarity and equality between women and men prevail”.
  - Article 3 TEU pledges the Union to “combat social exclusion and discrimination” and to “promote social justice and protection, equality between men and women, solidarity between generations and protection of the rights of the child”.
  - Article 6(1) TEU states that : “The Union recognises the rights, freedoms and principles set out in the Charter of Fundamental Rights of the European Union of 7 December 2000, as adapted at Strasbourg, on 12 December 2007, which shall have the same legal value as the Treaties. The provisions of the Charter shall not extend in any way the competences of the Union as defined in the Treaties”.

- Article 6(2) TEU states that: “The Union shall accede to the European Convention for the Protection of Human Rights and Fundamental Freedoms...”
- Article 6(3) TEU states that: “Fundamental Rights, as guaranteed by the European Convention for the Protection of Human Rights and Fundamental Freedoms and as they result from the constitutional traditions common to the Member States, shall constitute general principles of the Union’s law”.
- Article 7 sets out procedure for dealing with a “clear risk of a serious breach” by a Member State of the values referred to in Article 2.
- Article 9 TEU mandates the EU institutions to afford all citizens equal attention, and Article 21 TEU sets forth the requirement that the EU be guided by the principle of equality in EU external action.

- Although these articles do not create any rights, their prominent position in the TEU shows that the EU is committed to human rights and allows for more substantive forms of protection to be developed in the future.
- The TFEU contains a horizontal clause on non-discrimination provides the EU with a legal basis for the EU non-discrimination legislation.
  - Article 10 TFEU specifies that “in defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, **disability**, age or sexual orientation”.
  - Article 19 TFEU (former Article 13 EC) allows the EU to take action to combat discrimination on the named grounds his provides: “Without prejudice to the other provisions of the Treaties and within the limits of the powers conferred by them upon the Union, the Council, acting unanimously in accordance with a special legislative procedure and after obtaining the consent of the European Parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, **disability,** age or sexual

2. The European Charter of Fundamental Rights

- Since the entry into force of the Lisbon Treaty in December 2009, the Charter has acquired the same legal value as the EU Treaties and binds the EU institutions and member states when their action falls under the scope of application of EU law.

- The Charter incorporates a binding set of principles bringing together in one place all of the personal, civic, political, economic and social rights enjoyed by people within the European Union. The Charter includes the social and economic rights recognised as general principles of EU law, but also the fundamental rights adopted by the EU from the European Convention on Human Rights (ECHR) and the constitutional traditions common to the member states.

- Article 21(1) of the Charter provides for an all-embracing prohibition on discrimination states that: “Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited”.

- Article 26 of the Charter states that the “Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community”. These measures may concern education, vocational training, ergonomics, accessibility, mobility, means of transport and housing as well as access to cultural and leisure activities.

- Article 51 sets out the **scope of application** of the Charter:
  - Article 51(1) states that the provisions of the Charter are addressed to the institutions, bodies, offices and agencies of the Union with due regard for the principle of subsidiarity and to the Member States only when they are implementing Union law. They shall therefore respect the rights, observe the principles and promote the application thereof in accordance with their respective powers and respecting the limits of the powers of the Union as conferred on it in the Treaties. Thus the Charter binds also Member states whenever they act within the scope of EU law.
  - Article 51(2) reiterates the article 6(1) provision of the TEU: "The Charter does not extend the field of application of Union law beyond the powers of the Union or establish any new power or task for the Union, or modify powers and tasks as defined in the Treaties". This means that the Charter cannot enter new policy domain and only attaches to EU law which is the expression of agreement between Member states that the EU has competence in conformity with the subsidiarity principle.
- Since its adoption, the ECJ mainly relied on the on the Charter :
  - to give broad interpretation to human rights: Case C-391/09 Runevi-Vardyn v. Vilnius and Case C-159/10 Fuchs and Kőhler v Land Hessen.
  - to invalidate EU secundary legislation which breaches a Charter principle: Case C-92/09 Volker v Land Hessen, and Case C-236/09 Association Belge des Consommateurs Test-Achats ASBL v Conseil des Ministres,.

- In the **case C356/12** Glatzel v Freistaat Bayern, the ECJ for the first time had to assess the compatibility of EU provisions with the disability provisions of the Charter. The ECJ had to assess whether physical conditions for drivers settled in the Directive 2006/16 constitute discrimination on the grounds of disability and, hence, violate the principle of equal treatment (Article 20 of the Charter), and more specifically, the principle of non-discrimination on the grounds of discrimination (Article 21(1)) as well as the principle of integrating of integrating persons with disabilities (Article 26).

- The ECJ eventually concluded that it did not have sufficient information to conclude that the Directive should be invalidated but there are several interesting elements to notice in its judgment :

  a) the ECJ considered that Article 26 of the Charter "does not require the EU legislature to adopt any specific measure" for persons wit disabilities and that '"in order for that article to be fully effective, it must be given more specific expression in EU law or national law".

  b) the reference to the UN Convention on the Rights of Persons with Disabilities as an integral part of the European Union legal order and the Directive 2006/126 as regard personal mobility considered as one of the legal acts of the European Union which refer to matters governed the UNCRPD.

  c) the way in which the ECJ carefully examined whether there is an objective justification for different treatment of some disabled drivers (suitability , necessity and proportionality)

  d) the lack of necessity to determine whether a diminished visual acuity should be considered to amount to a disability within the meaning of the Charter since a difference in treatment consisting in not issuing a driving licence for vehicles on the ground of insufficient visual acuity may be objectively justified in the light of overriding considerations of road safety.

3. The United Convention on the Rights of Persons with Disabilities (UNCRPD) as part of the EU legal order

- The European Union has acceded to the UNCRPD with Council Decision 2010/48/EC. The instrument of ratification was deposited in December 2010, after the adoption of a Code of Conduct by the Council. The Council Decision has 2 substantive legal bases, namely Article. 19 TFEU (non discrimination) and article 114 TFEU (measures aiming to improve the conditions for the establishment and functioning of the internal market) , in conjunction with the procedural provision of article 218 TFEU (agreements between the Union and third countries or international organisations).

- It was the first time ever that the EU becomes a party to an international human rights treaty and it was also the first time that an intergovernmental organization join a United Nations human rights treaty.

- The UNCRPD, as other multilateral agreements that make provision for participation by regional organisations such as the EU alongside its Member States, provides for a Declaration of competence specifying which areas of the agreement fall within the competence of the Regional organization and which within that of its Member States. This Declaration is intended to specify to third Countries the distribution of competences between the European Union and the Member States and is also is relevant to determine the ultimate international responsibility for the implementation of the UNCRPD.

- The UNCRPD is **a mixed agreement**. Mixed agreements are signed and concluded by the EU and its Member States on the one hand, and by a Third Party on the other hand. The mixed nature is due to the fact that part of an international agreement falls within the scope of the EU powers and part within the scope of the powers of the Member States.

- An international agreement has legal effect in the EU legal order and does not require further acts of implementation at EU level such as a regulation or a directive. Moreover, in the hierarchy of sources of EU law, international agreements concluded between the EU and third countries or international organisations are situated below primary sources and general principles of EU law, but above secondary sources. The ECJ held that international agreements and all acts of the EU institutions adopted in relation to their conclusion prevail over secondary sources of EU law.

- As a result, all EU unilateral measures such as regulations, directives and decisions must be in conformity with international agreements in so far as their provisions fall within the scope of Community competence. Any conflicting secondary legislation may be annulled by the ECJ by virtue of Article 263 TFEU.

- The primacy of international agreements concluded by the Community over provisions of secondary Community legislation means that such provisions must, so far as is possible, be interpreted in a manner that is consistent with those agreements (ECJ Case C-61/94). The accession to the UNCRPD creates therefore an obligation to interpret EU law in manner that is consistent with the Convention (Ring vs Dansk almennyttigt Boligselskab DAB – ECJ Case C2335/11).

- Under certain conditions (see infra), international agreements can be invoked before the court by an individual; there is direct effect (Demirel - Case 12/86).

- In ensuring compliance with commitments arising from an agreement concluded by the Community institutions, the Member States fulfil, within the Community system, an obligation in relation to the Community, which has assumed responsibility for the due performance of the agreement (Case C-239/03, Etang de Berre). Therefore, the Commission might bring an infringement case against Member State not properly implementing the UNCRPD insofar as its provisions are within the scope of the EU competence.

4. Secondary EU legislation protecting the rights of persons with disabilities

- There is a very broad and diverse legislation at the European level dealing with disability related issues. Disability is part of the non-discrimination EU policy together with gender, ethnic origin, religion or belief, age and sexual orientation. Disability related issues are also covered by EU legislation and programmes in the field of education, employment and training, health and safety at work, social protection, social inclusion, public procurement, state aids, transport, telecommunications, consumer protection, health services and bioethics, assistive technologies etc.
- Article 19 TFEU has been the legal basis for the Council Directive 2000/78/EC of 27 November 2000, known as the Employment Equality Directive. As provided for in Article 1, the purpose of this Directive is to lay down a general framework for combating discrimination on the grounds of religion or belief, disability, age or sexual orientation a regards employment and occupation, with a view to putting into effect in the Member States the principle of equal treatment.
- This directive bans both direct discrimination (differential treatment based on a specific characteristic) and indirect discrimination (any provision, criterion or practice which is apparently neutral, but is liable to adversely affect one or more specific individuals or incite discrimination). Harassment, which creates a hostile environment, is also deemed to be a form of discrimination.

- Among the substantive provisions of the Directive figures an article on reasonable accommodation. As defined by Article 2 of the UNCRPD, reasonable accommodation means that the employer has a legal duty to take measures to adapt to working place to an employee with disabilities, such as removing physical barriers by installing ramps, facilitating access of visually impaired employees to information technologies, or altering working times to accommodate the needs of workers with disabilities. Failure to provide reasonable accommodation constitutes discrimination for the purpose of the Directive.
- The Employment Equality Directive requires Member States to provide for effective judicial remedies, embed legal rules on shifting the burden of proof to the respondent where a prima facie case of discrimination is established, and provide for sanctions. Notably, the Employment Equality Directive imposes only minimum requirements, and allows Member States to apply provisions which are more favourable to the protection of equal treatment than those laid down in the Directive.

- In 2008, the Commission presented a Proposal for a new Equal Treatment Directive aiming at extending the EU's non-discrimination legislation beyond the sphere of employment and occupation, addressing discrimination in the fields of social protection, social advantages, education, and access to and supply of public goods and services. However, this proposed Directive is still subject to an ongoing discussion and negotiation in Council. As yet, it has not been possible to achieve the unanimous agreement of all Member States that is required for the adoption of directives based on Article 19 TFEU, meaning the directive is far from being approved.

- On 2 December 2015, the European Commission also adopted a proposal for a European Accessibility Act, namely a directive aiming at prescribing common accessibility requirements covering products and services across the EU. Discussions among the Member states in the European Council and in the Parliament are still underway and it is too early to say when the final adoption of the proposal could be expected.

- Article 153 of the Treaty on the Functioning of the European Union gives the EU the authority to adopt directives in the field of safety and health at work. Reference is made in the Framework Directive and individual directives to the protection of the health and safety of workers with disabilities – for instance through the provision in Directive 89/654/EEC on the minimum safety and health requirements for the workplace stipulating that employers are required to organise workplaces "to take account of handicapped workers, if necessary". In 2015, the ECJ concluded the Fenoll case (C-316/13) that the concept of "worker" as stipulated in of Directive 2003/88 on working time and Article 31 of the Charter of Fundamental Rights must be interpreted in such a way that a person in a sheltered workplace, performing work which was not entirely marginal, should be covered by the definition of worker.

- Disability is also addressed to some extent in EU consumer law, most notably in the Unfair Commercial Practices Directive (2005/29), the Product Safety Directive (2001/95) and the Consumer Rights Directive ((2011/83). However, the conceptualisation of vulnerability under EU consumer law remains inadequate to provide the adequate protection for persons who are disadvantaged on grounds of their disability.

- Disabled passengers rights are protected at European level by an set of comprehensive regulations which covers all means of transportation: planes, trains, ships and buses or coaches.
- The Regulation 1107/2006 concerning the rights of disabled persons and persons with reduced mobility when travelling by air establishes a set of specific rights for passengers with disabilities. The basic principles of this regulation are:
    - persons with disabilities should not be discriminated against when booking a ticket or boarding an airplane;
    - persons with disabilities have the right to receive assistance at the airport at no additional charge;
    - all staff dealing directly with the traveling public must receive relevant training, including disability awareness training.
- Regulation 261/2004 establishing common rules on compensation and assistance to passengers in the event of denied boarding and of cancellation or long delay of flights, establishes rules for compensation but also regarding the liability of airlines for damaged, lost, or destroyed mobility equipment.
- Similar to the air- passengers' rights regulations, disabled passenger's rights are addressed in :
    - the Regulation 1371/2007 when travelling by train;
    - the Regulation 1177/2010 when travelling by sea and inland waterway;
    - the Regulation 181/2011 when traveling in bus and coach transport.

- Since the EU law on passengers rights is framed in regulations, it is **directly applicable**. They do not need any other acts of parliament in the member state to make them into law. These regulations are also **vertically and horizontally directly effective** : they can be used as a piece of law in a member state court against the state or another individual.

5. Issues of primacy, direct and indirect effect

- The primacy of European Union law (sometimes referred to as supremacy) is an EU law principle that when there is conflict between European law and the law of Member States, European law prevails; the norms of national law have to be set aside. This principle was developed by the European Court of Justice, and, as interpreted by that court, it means that any norms of European law always take precedence over any norms of national law, including the constitutions of Member states.
- Direct effect is another principle of the EU law developed by the ECJ. It enables individuals to immediately invoke a European provision before a national or European court. This is significant because of the consequences both within the legal order of the European Union and for its member states.
- For example, if the provisions of the UNCRPD would be directly effective in the EU legal order, they will also have direct effect within the legal orders of all member states and, as EU law, enjoy supremacy over national law. EU law thus could act as a door opener for the UNCRPD in the member states' legal orders and provides an enforcement mechanism and potentially also an hierarchical boost : the UNCRP provisions could be enforced by all mechanisms used to enforce EU law, in particular by national courts, and it will benefit from the doctrine of supremacy of EU law according to which it enjoys a higher rank than member states' legislation.

- The term ‘direct effect’ was first used by the Court of Justice of the European Union (CJEU) in a judgement on 5 February 1963 when it attributed, to specific treaty articles, the legal quality of direct effect in the case of NV Algemene Transporten Expeditie Onderneming van Gend en Loos v. Nederlandse Administratie der Belastingen (Case 26/62). In this case, the CJEU identified three situations necessary to establish the direct effect of primary EU law. These are that:
    - the provision must be sufficiently clear and precisely stated
    - it must be unconditional and not dependent on any other legal provision;
    - it must confer a specific right upon which a citizen can base a claim.
- Taken together, the principles of direct effect and primacy mean that treaty provisions may be used to make claims before domestic courts and override domestic law. Probably the best-known example is Defrenne v. Sabena (Case 43/75), where the CJEU decided that the principle that women and men should receive equal pay, which is laid down by Article [141 EC now 157 TFEU], may be relied on before the national courts. These courts have a duty to ensure the protection of the rights, which that provision vests in individuals.
- “Vertical” effect applies when provisions have direct effect between citizen and public bodies. “Horizontal” effect‘ applies when the provisions have direct effect between citizen and citizen.

- The principle of direct effect also applies to the EU secondary legislation :
  - decisions are binding in their entirety upon those to whom it is addressed (not general, but specific)
  - regulations are directly applicable in all member states. They are self-executing.
  - directives are not directly applicable-no self-executing character. Their Transposition in domestic law is in principle required but they are exceptions (non implementation by the member States, precise and clear provisions).
- The principles of direct effect also applies to mixed agreements s (Case 12/86 Demirel) insofar as the provisions of the agreement at stake:
  - address areas already largely covered by Community law (Case C-239/03 Commission v France -Etang de Berre)
  - are sufficiently clear, precise and unconditional (Case C-192/89 Sevince)
- In the case Z v The Board of management of a community school (C-363/12), the ECJ held that the provisions of the UNCRPD are not, as regards their content, provisions that are unconditional and sufficiently precise and therefore **do not have direct effect** in European Union.

ERA Seminar
Disability-related Financial Instruments in light of EU Law and the UNCRPD

CASE STUDY

The concept of disability in EU law and its impact on national legislation

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Programme

- 11:45 **Case study on the concept of disability in EU law**
  Introduction to the facts of the case
- 12:00 **Working groups discussion**
- 12:30 **Discussion of the results**

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Disability under EU Law

Who is protected ?

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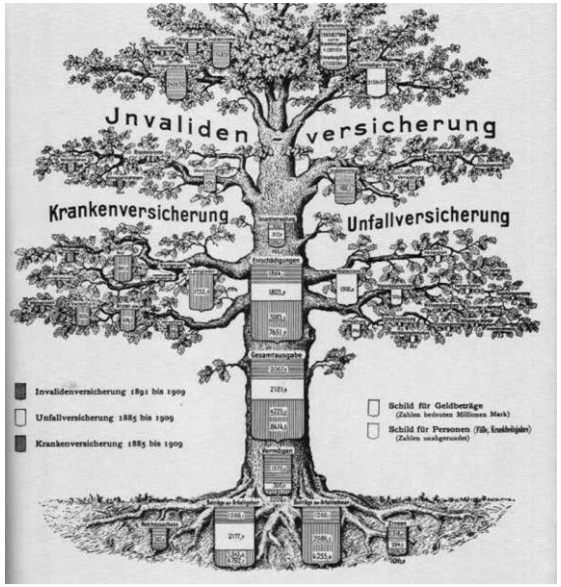
PROBLEM: A wide variety of legal criteria are used by the Member States and within each Member State to define who is eligible from among the population of persons with disabilities.

The primary legislation for the purposes of EU parking permit defines a disabled person as a "person with a permanent condition or disability that severely restricts their ability to walk"

A person should be considered disabled if his "ability to earn a living is permanently reduced to less than one third caused by illness or other impairment".



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Possible answers on the problem

"The way in which disability is understood and legally defined is rooted in the social, cultural and historical context of each Member State. Therefore, any EU law should merely refer to the laws of the Member States for the definition of that concept".

OR

"The principle of equality require that the terms of a provision of EU law addressing disability must be given an independent and uniform interpretation throughout the EU."

Discussion : What is your opinion on these two approaches ? Pros and cons?

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In the Chacon Navas Judgement (C-13/05), CJEU decided as follows :

- The concept of “disability” for the purpose of Equal Treatment Directive (200/78) must be given an autonomous and uniform interpretation throughout the Community

- The scope of the Directive cannot be extended by analogy on other grounds than those listed exhaustively in the Directive. Sickness cannot be therefore regarded as such as a ground of discrimination.

In Ring (C-335/11), the CJEU adopted a revised definition of disability for the purpose of the Directive 2000/78

The Directive 2000/78 must, as far as possible, be interpreted in a manner consistent with the United Nations Convention on the Rights of Persons with Disabilities".

The concept of "disability" must be understood as referring to a limitation which results in particular from physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers.

What says the UNCRPD about the matters covered by the Directive 2000/78?

Article 27 : Work and employment

States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:

a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;

Article 2 – Definitions

For the purposes of the present Convention:

"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;

"Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

Article 1 – Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

A practical case solving example of disability rights under EU Law

FACTS OF THE CASE

- Joe, a customer service adviser, was employed by a company providing insurance services. Joe had worked for the company without incident from 2000. However, between 2016 and 2018 Joe was off work for a range of different reasons; including a bipolar affective disorder, a recurring form of depression. . According to a medical diagnosis, these health problems were aggravated by external factors such as a tremendous workload .
- Joe's doctor ultimately advised that his absence was a result of his depression and provided his employer with medical certificates confirming the reason for, and duration of, his absence.
- In 2018, the company dismissed Joe on the grounds of the cumulative duration of his absences and on the basis of a provision of his national law which provides that an employer is entitled to dismiss an employee for absences from work which amount to 20% of the employee's working hours in two consecutive months.
- Joe claimed that, as his absence from work was caused by his disability, the legal provision discriminated against him because he was disabled.

Working groups discussion

- Have you had some practical experience of a domestic law similar to the one involved in Joe‘s case ?
- Is there applicable EU law for Joe’s case ?
  - Material : Charter of Fundamental Rights / UNCRPD / Secondary legislation
  - Personal : Is “Depression” covered by disability ?
- Does there seem to be discrimination ?
  - Direct discrimination
  - Indirect discrimination
  - Denial of reasonable accommodation
- Can the contested rule be justified, meaning that there is ultimately no discrimination?

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Disability and mobility: Unpacking the benefits package

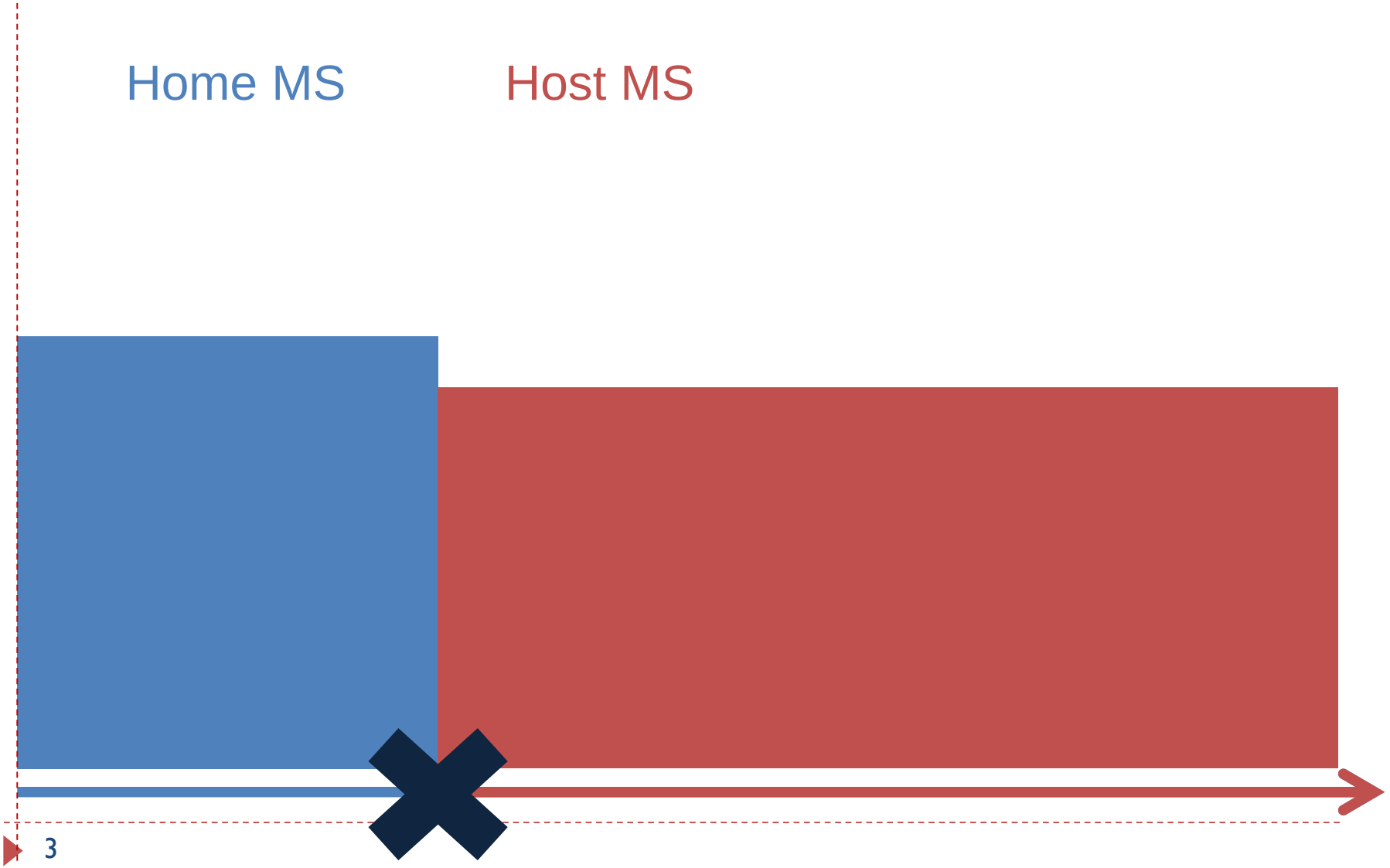
Nicolas Rennuy (York)

Continuous protection: Export by home MS

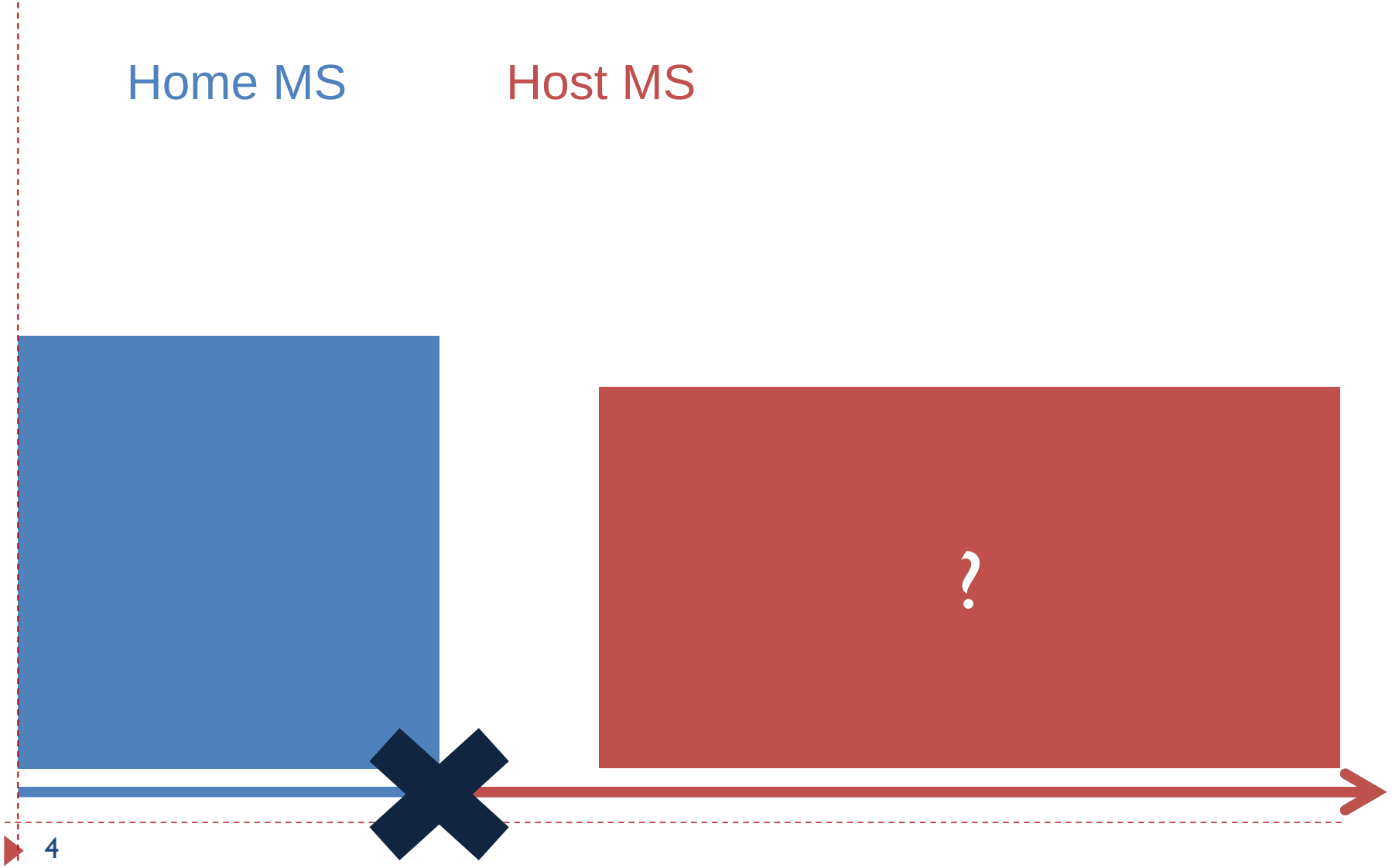
Home MS

Host MS

Continuous protection: Instant shift to host MS



Discontinuous protection: Delayed shift to host MS



EU law

- Sources of rights
  - Regulation 883/2004 on the coordination of social security systems
  - Treaty on the Functioning of the European Union
  - National law
    - C-352/06 *Bosmann*

Benefits packages

- Form of benefit
  - Benefits in kind
  - Benefits in cash
  - Discretionary benefits
  - …

Benefits packages

- Invalidity benefits
  - Regulation 883/2004, Chapter 4
- Long-term care
  - Regulation 883/2004, Chapter 1
- Special non-contributory benefits
  - Regulation 883/2004, Chapter 9
- Rehabilitation measures
  - Regulation 883/2004, Chapter 1*
- Benefits covering disability caused by an act of war, wartime imprisonment or post-war repression
  - Treaty on the Functioning of the European Union
- Others
  - Treaty on the Functioning of the European Union

Regulation 883/2004

- ‘a benefit may be regarded as a social security benefit if it is granted to the recipients, without any individual and discretionary assessment of personal needs, on the basis of a legally defined position and relates to one of the risks expressly listed in Article 3(1) of Regulation No 883/2004’
  - ‘the discretionary assessment of the individual needs of the recipient of the benefit in question must, above all, relate to eligibility for the benefit’
    - C-679/16 *A*

Invalidity benefits

Scope

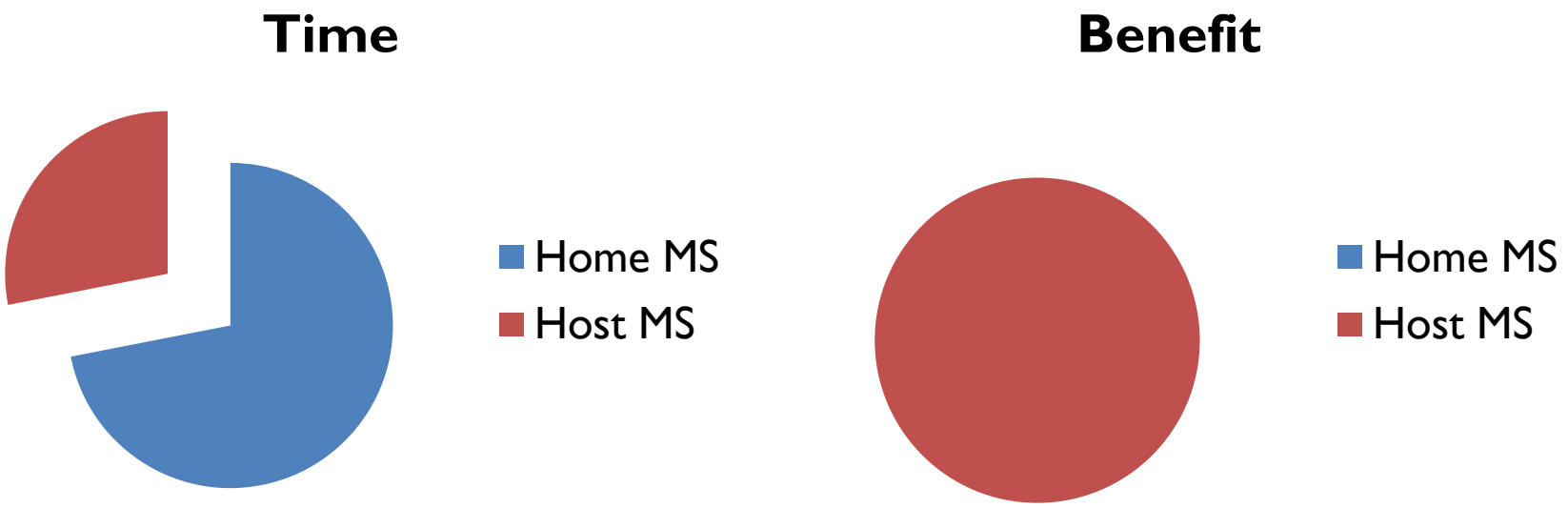
- Invalidity benefits are 'intended, as a general rule, to cover the risk of disability of a prescribed degree, where it is probable that such disability will be permanent or long-term'
  - C-503/09 *Stewart*

- 'benefits which are not related to the "earning capacity" of the insured person cannot be regarded as invalidity benefits within the meaning of Article 2(1)(b) of Regulation No 3[/58]'
  - Case 14/72 *Heinze*
  - 'the incapacity for work followed by invalidity' (art. 44(2) Reg. 883/2004, art. 46(2) Reg. 883/2004, art. 48(3) Reg. 883/2004, and art. 45(1) Reg. 987/2009)

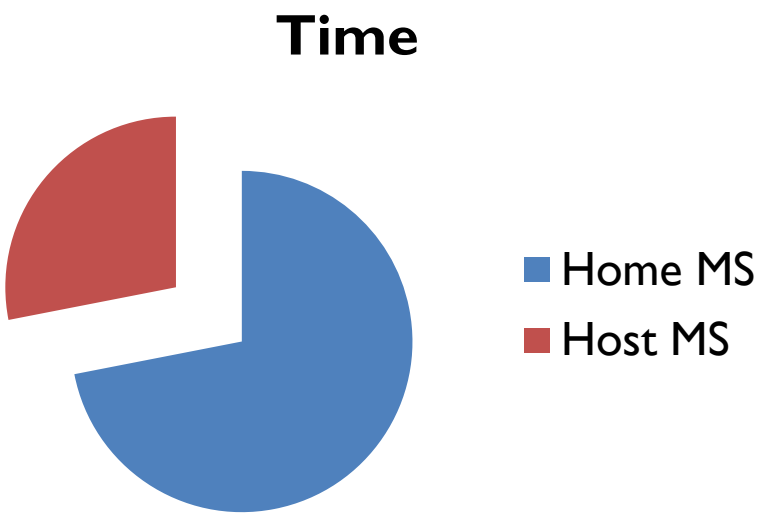
Scope

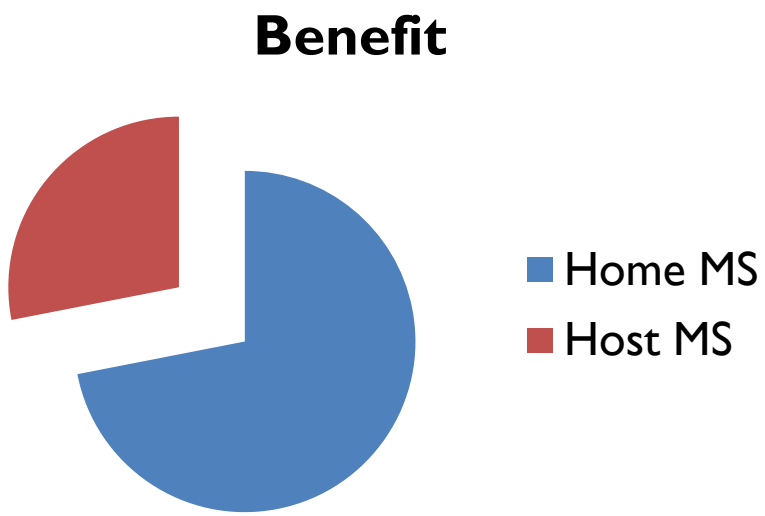
- Versus sickness benefits
  - Sickness benefits cover 'the risk connected to a morbid condition involving temporary suspension of the concerned person's activities.'
    - C-503/09 *Stewart*
  - Duration
- Versus unemployment benefits
  - Capacity to work
- Versus special non-contributory cash benefits
  - Benefits intended to provide 'solely specific protection for the disabled, closely linked to the said person's social environment in the Member State concerned'
  - Non-contributory
  - Listed in Annex X

The allowance method



The pension method





Which MS? Which law?

- Title II Reg. 883/2004
  - Person with disability who does not work: from MS of work to MS of habitual residence
  - Unless Title III provides otherwise
- Title III, Chapter 4: the allowance method
  - The legislation that applied at the moment of the occurrence of the incapacity for work leading to invalidity
- Title III, Chapter 5: the pension method
  - All the legislations to which a person has been subject prior to the moment of the occurrence of the incapacity for work leading to invalidity
- In both cases: full portability*

Long-term care

Scope

- Dynamic Court …
  - Coordination as atypical sickness benefits:
    - C-160/96 *Molenaar*: sickness benefits
    - C-388/09 *da Silva Martins*: atypical sickness benefits
    - C-679/16 *A*: medical concept?
- … and timid legislator?

Currently	Proposed
An article (34)	A chapter (1a)
Otherwise rules on sickness benefits	Otherwise rules on sickness benefits
Defined only in case-law	A definition
A rough list	A detailed list

Scope

- Current definition(s)*
  - 'the notion of dependence refers, in essence, to a situation in which, as a result of his reduced autonomy, a person is reliant on the assistance of others in order to carry out the basic routines of everyday life'
    - C-562/10 *Commission v Germany*
  - 'intended to improve the state of health and quality of life of persons reliant on care'
    - C-430/15 *Tolley*
  - Minus 'quality of life'?
    - C-679/16 *A*
- Proposed definition
  - 'any benefit in kind, cash or a combination of both for persons who, over an extended period of time, on account of old-age, *disability, illness or impairment*, require considerable assistance from another person or persons to carry out essential daily activities, including to support their personal autonomy; this includes benefits granted to or for the person providing such assistance'

Which MS? Which law?

- Benefits in cash
  - Portable
    - Art. 7 and 21 Reg. 883/2004
- Benefits in kind
  - Person resides outside the competent State
    - Insured in competent State
    - State of habitual residence provides its benefits in kind (if any)
    - Competent State fully reimburses State of residence
- Combinations of benefits in cash and in kind

Special non-contributory cash benefits

Scope

- Listed in Annex X
- Cash
- Non-contributory
- Special
  - ‘because of its personal scope, objectives and/or conditions for entitlement, has characteristics both of the social security legislation referred to in Article 3(1) and of social assistance.’
  - ‘intended to provide […] solely specific protection for the disabled, closely linked to the said person's social environment in the Member State concerned’

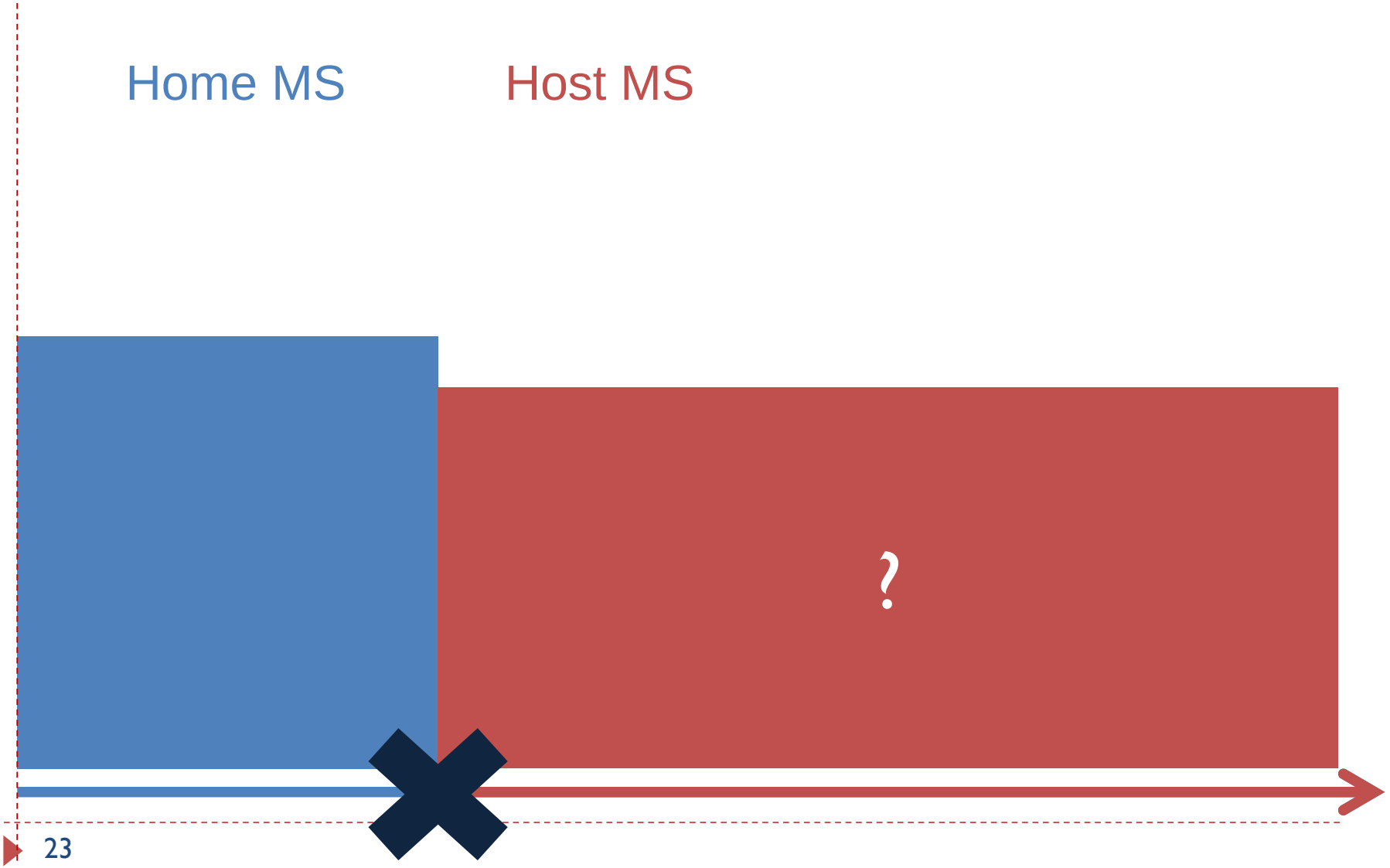
Scope

- Not special:
  - 'the benefits at issue do not have that sole function. In fact, although they unquestionably promote the independence of the persons who receive them and protect the disabled in their national social context, they are also intended to ensure the necessary care and the supervision of those persons, where it is essential, in their family or a specialised institution.'
    - C-299/05 *Commission v Council and Parliament*
  - Long-term care
    - E.g. C-286/03 *Hosse*
- Special:
  - A benefit promoting the social integration and independence of disabled persons, the amount of which reflects the costs resulting from the mobility problems, even though it is not means-tested.
    - C-537/09 *Bartlett*

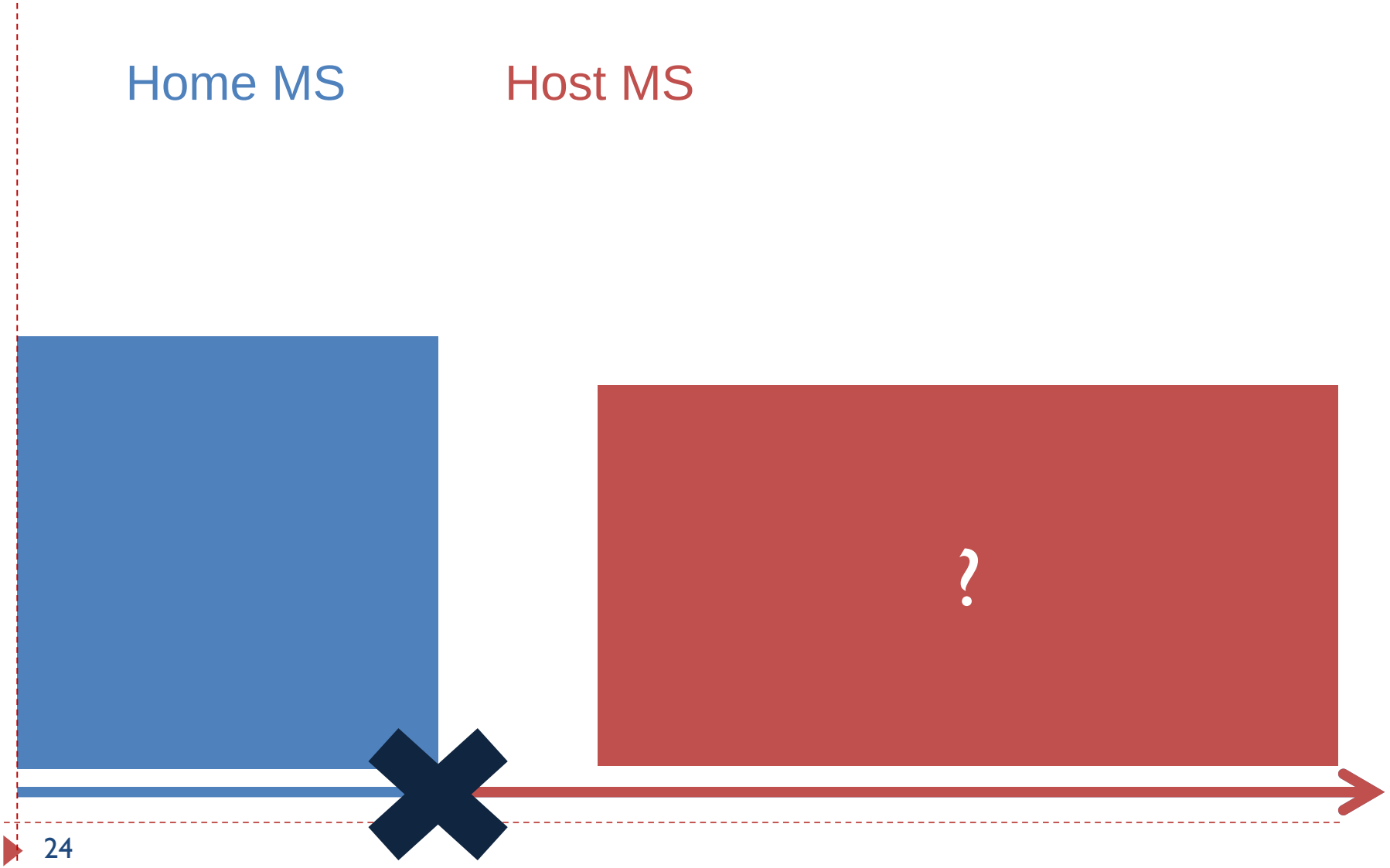
Which MS? Which law?

- Competent State: State of habitual residence
- Relocating: shift to new State of habitual residence
- No portability, unless
  - C-20/96 *Snares* (former worker): no export
  - C-287/05 *Hendrix* (worker): export
  - C-537/09 *Bartlett* (former workers?): no export
  - C-503/09 *Stewart* and C-679/16 *A* (economically inactive persons; not SNCBs): export

Instant shift to host MS?



Instant shift to host MS?



Which MS? Which law?

- Relocating: shift to new State of habitual residence
  - C-333/13 *Dano*
  - Economically inactive persons
    - Former worker / family member of worker / five years of continuous and lawful residence
    - Others
      - If sufficient resources, then right to reside, then right to equal treatment, including for benefits
      - If insufficient resources, then no right to reside, then no right to equal treatment, including for benefits

Other sources of rights

TFEU

- Article 45
  - 1. Freedom of movement for workers shall be secured within the Union
  - 2. Such freedom of movement shall entail the abolition of any discrimination based on nationality between workers of the Member States as regards employment, remuneration and other conditions of work and employment.
- Article 21
  - 1. Every citizen of the Union shall have the right to move and reside freely within the territory of the Member States, subject to the limitations and conditions laid down in the Treaties and by the measures adopted to give them effect.

TFEU

- C-287/05 *Hendrix* (worker) export
  - Real link: 'the worker in question has maintained all of his economic and social links to the Member State of origin.'
- C-537/09 *Bartlett* (former workers?) no export
  - No discussion of TFEU / real link
- C-503/09 *Stewart* (ec. inactive person) export
  - Real link: past entitlement + connection to social security system + family circumstances + nationality + durational residence
- C-679/16 *A* (student) export
  - Real link: habitual residence + weekly return

Unpacking the benefits package

Fragmentation I

	Competent for	Benefit offered	Total
Last MS of work	Invalidity benefit	SNCB (€1000)	€0
MS of residence	SNCB	Invalidity benefit (€1000)	€0

Fragmentation II

	Competent for	Benefit offered	Total
Competent MS	Long term care benefit in cash	Benefit in kind only (value of €1000)	€0
MS of residence	Long term care benefit in kind	Benefit in cash only (€1000)	€0

- C-208/07 *von Chamier-Glisczinski*

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Persons with disabilities & Europe 2020

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www.disability-europe.net

Results from

ANED
European Network of Academic Experts in the Field of Disability

European Commission: DG Employment, Social Affairs and Inclusion

Source of data: EU-SILC 2015 & Eurobarometer 2015

DEFINITION OF PEOPLE WITH DISABILITIES

EU-SILC	UN CONVENTION
Limitation in activities people usually do because of health problems for at least the last 6 months **Answers** 1. yes, strongly limited 2. yes, limited 3. no, not limited **Age:** 16+ living in private households	Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in **interaction** with various **barriers** may hinder their full and effective participation in society on an equal basis with others.

Special Eurobarometer 2015 on Discrimination:

1. **"In the past 12 months have you personally felt discriminated against or harassed on disability".**
2. **"Where you live, do you consider yourself to be part of a minority in terms of disability".**

Age: 15+

EU-SILC

Persons receiving disability related benfits. Age: 16-64

Source: Eurostat and UN CRPD

THE EU-SILC PROXY OF DISABILITY

EU-SILC	UN CONVENTION
General activity limitation The variable measures the respondent's self-assessment of whether he/she is hampered in "activities people usually do", by any on-going physical or mental health problem, illness or disability. It includes all types of disability but it relies on a medical approach and excludes people in institutions. The health-related cause aims to exclude limitations due to financial, cultural or other causes. Requires a minimal period of at least 6 months	Stresses "interaction with various barriers" and "full and effective participation in society".

Alternative proxies:

ADL: Rely exclusively on medical criteria and aims to meet the criteria of national health systems

Washington group: It relies on a restrictive list (furthermore, the 'Short Set on Functioning' excludes psychological and other disabilities). But provides information on the nature of disability.

Source: Eurostat and UN CRPD

THE EU-SILC PROXY OF DISABILITY

Statistical & other criteria

The General activity limitation question can be introduced at a **low cost** in different surveys aiming to monitor and assess different socio-economic policies.

The large concept (all persons with limitations) provides indicators with **lower standard errors** compared to the narrow concept (strongly limited), notably for employment, unemployment, etc.

The General activity limitation question is relevant **for adults** but needs adaptations in the case of children. It does not provide information on the nature of disability.

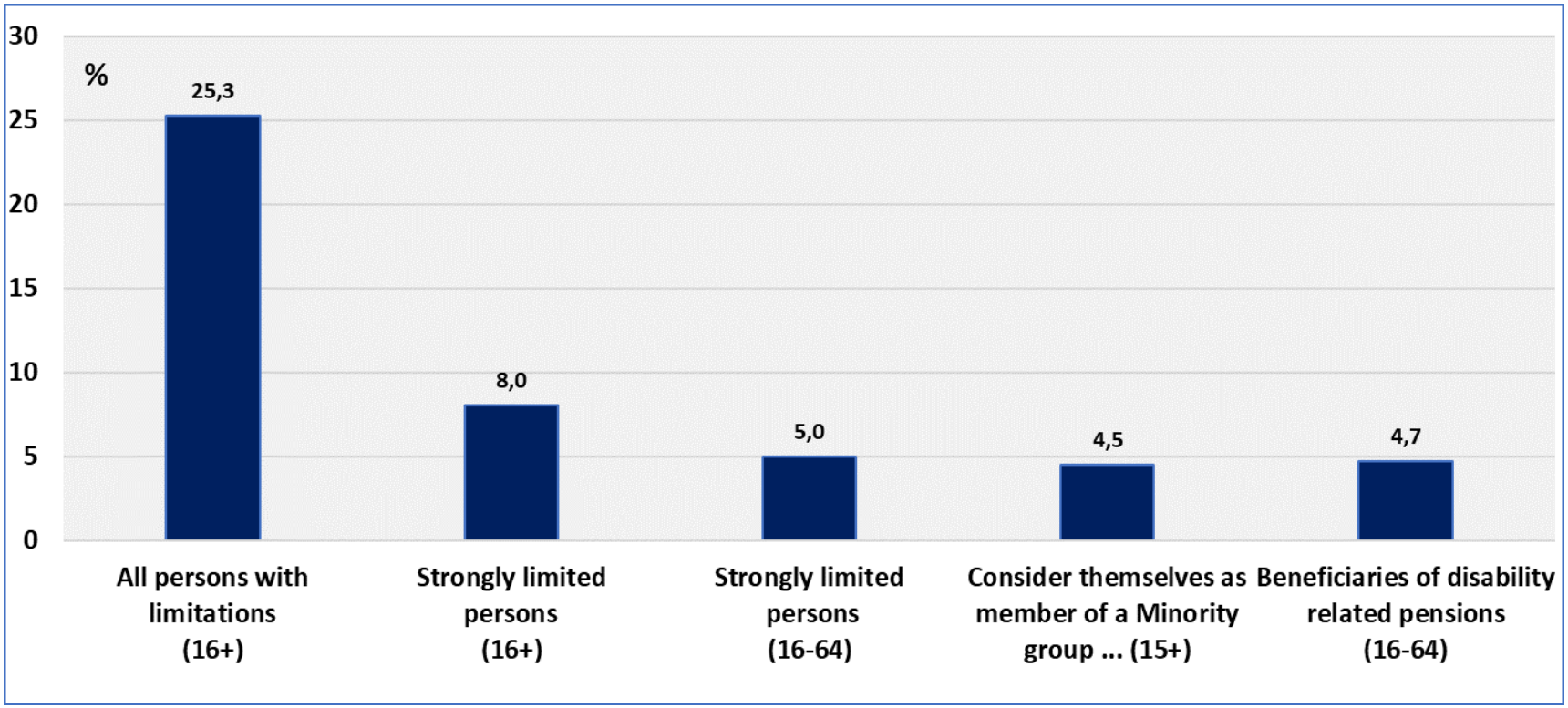
The inclusion of people in **institutions** in different surveys raises specific statistical issues.

Administrative data could complete certain surveys, notably those on education where national administrative registers are numerous but not comparable across countries.

Alternative proxies (ADL & WG):
They provide results close to those covering persons with severe limitations in the EU-SILC survey.
They provide information on a certain number of disabilities.

Source: Eurostat and UN CRPD

NUMBER OF PERSONS WITH DISABILITIES IN THE EU

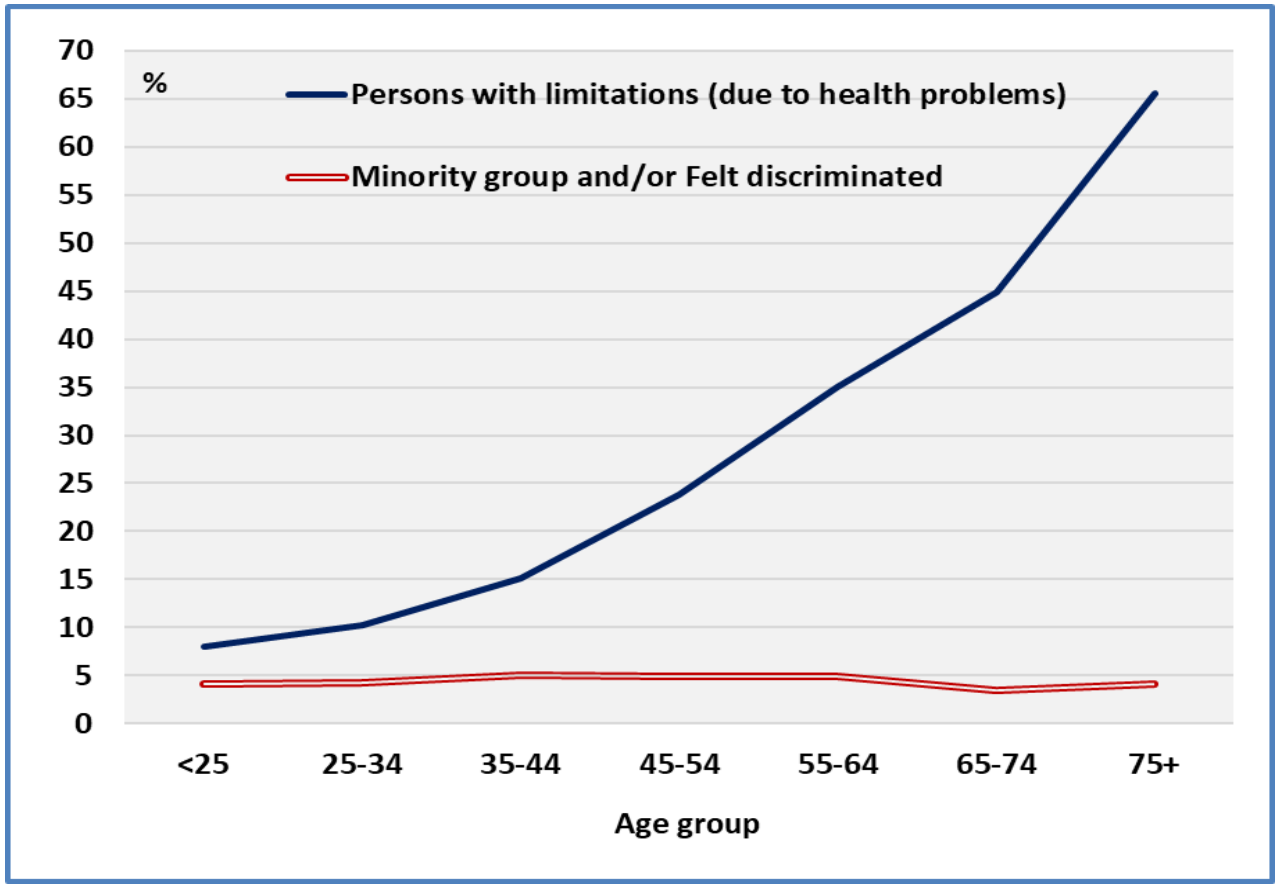


1. There is a big difference between all persons with limitations and persons with severe limitations.
2. About 8.0% report a severe limitation in the EU. This represents 32.8 mio persons aged 16+ in the EU.
3. About 4.5% consider themselves to be part of a minority in terms of disability and / or have personally having felt discriminated against or harassed on disability (Eurobarometer 2015, age: 15+).
4. About 4.7% receive a disability related pension (EU-SILC 2015, age: 16-64)

EU SILC UDB 2015 & Eurobarometer 2015

NUMBER OF PERSONS WITH DISABILITIES BY AGE ROUP IN THE EU

The percentage of persons with disabilities (limitations) increases with age. Health reasons play an important role. But the percentage by age group of those considering to be members of a minority group remains stable with age



EU SILC 2015 & Eurobarometer 2015

CESEP

EUROPE 2020: EU HEADLINE TARGETS

	Selected areas	Headline targets (EU)		Indicators (2010)
1.	EMPLOYMENT	75 % of the population aged 20-64 should be employed	1.	Employment rate by gender, age group 20-64
2.	EDUCATION	The share of early school leavers should be under 10% and at least 40% of 30-34 years old should have completed a tertiary or equivalent education	2.1	Early leavers from education and training by gender
			2.2	Tertiary educational attainment by gender, age group 30-34
3.	POVERTY & SOCIAL EXCLUSION	Reduction of poverty by aiming to lift at least 20 million people out of the risk of poverty or exclusion	3.1	People at-risk-of-poverty or social exclusion (union of the three sub-indicators below).
			3.2	People living in households with very low work intensity (<20%)
			3.3	People at-risk-of-poverty after social transfers (<60% nat. median hous. Inc.)
			3.4	Severely materially deprived people (4 or + items over 9) (& socially: 4/13)

Source: Eurostat

EUROPE 2020

EMPLOYMENT

TARGET (EU Headline)

- **75 % of the population aged 20-64 should be employed**

But each Member State has adopted its own national target.

At the EU level, about 47.4% of persons with disabilities are employed compared to 73.1% of persons without disabilities (EU-SILC 2015).

The employment rate of women with disabilities is 44.7% (EU-SILC 2015)

There is a potential for increasing the employment rate of people with disabilities with the relevant work place adaptations and technical aids.

EUROPE 2020

EDUCATION

TARGET (EU Headline)

- **The share of early school leavers aged 18-24 should be under 10% and**
- **at least 40% of 30-34 years old should have completed a tertiary or equivalent education**

But each Member State has adopted its own national target.

At the EU level, 22.0% of young disabled aged 18-24 are early school leavers compared to 11.7% for non-disabled young persons (EU-SILC 2015).

The rate of persons with disabilities who have completed a tertiary or equivalent education is 29.4%. This rate is 43.0% for persons without disabilities (EU-SILC 2015).

The high rates of early school leavers and low rates with a tertiary education among persons with disabilities might indicate problems related to accessibility and absence of adapted programmes..

EUROPE 2020

People at-risk-of-poverty after social transfers

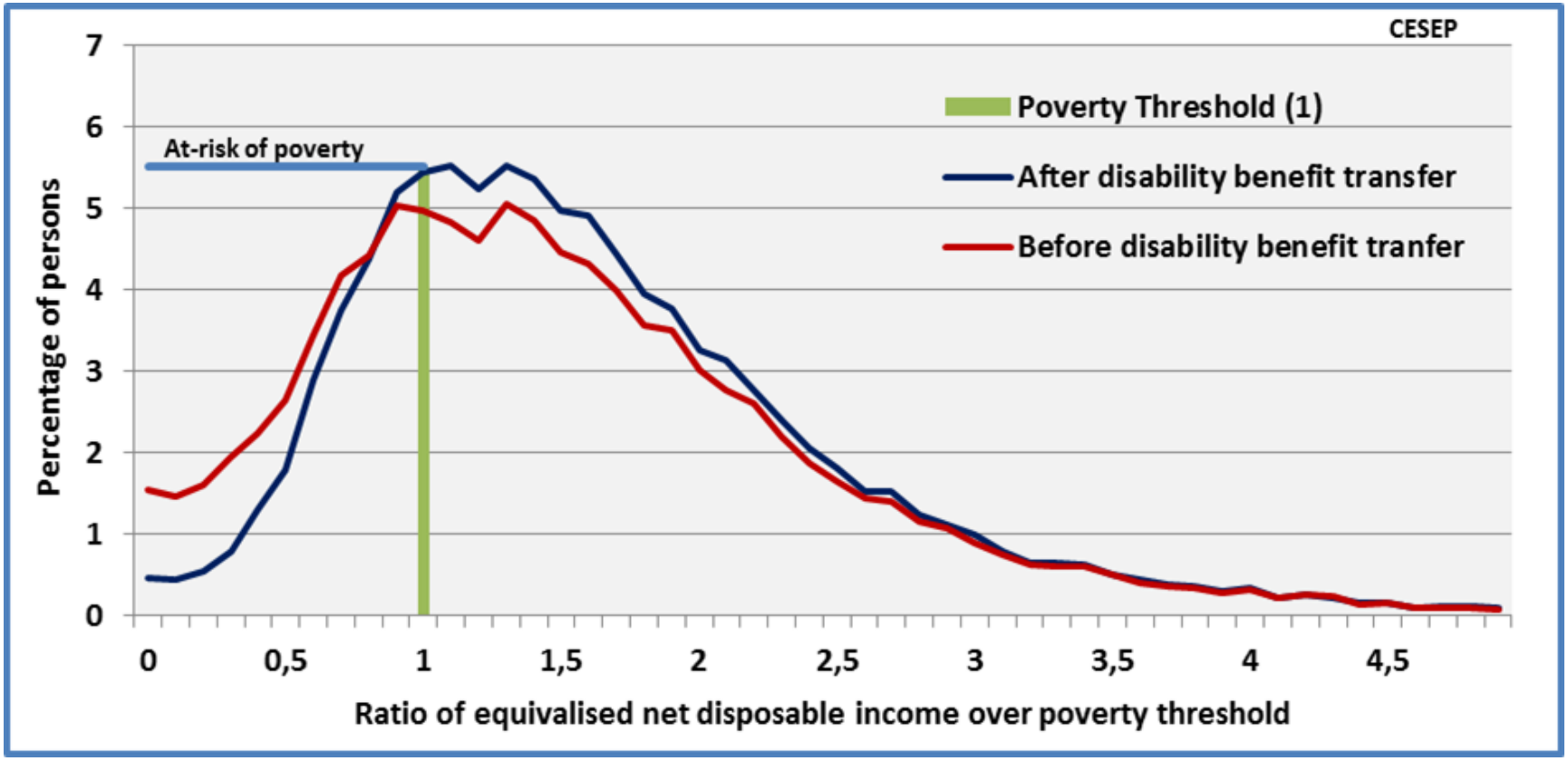
The risk of poverty means that a person lives in a household with a household equivalised disposable income less than 60% of the median national household equivalised disposable income (after social transfers).

At the EU level, in 2015, about 20.0% of persons with disabilities aged 16 and over face a risk of poverty compared to 15.4% of persons without disabilities of the same age group (EU-SILC 2015).

1. **People with disabilities face a higher risk of poverty after social transfers compared to people without disabilities. Also, they are concentrated near the poverty threshold.**
2. **Disability benefits reduce the poverty rate of persons with disabilities by 7 percentage points.**
3. **The method used to estimate financial poverty might under-estimate poverty among persons with disabilities because certain allowances aiming to compensate a disadvantage (e.g. transport/mobility - barriers) are treated as income.**

The impact of disabity related benefits in the EU

Persons with disabilities: Distribution of net disposable income before and after gross disability benefit transfers. Disability benefits reduce poverty by 7 percentage points.

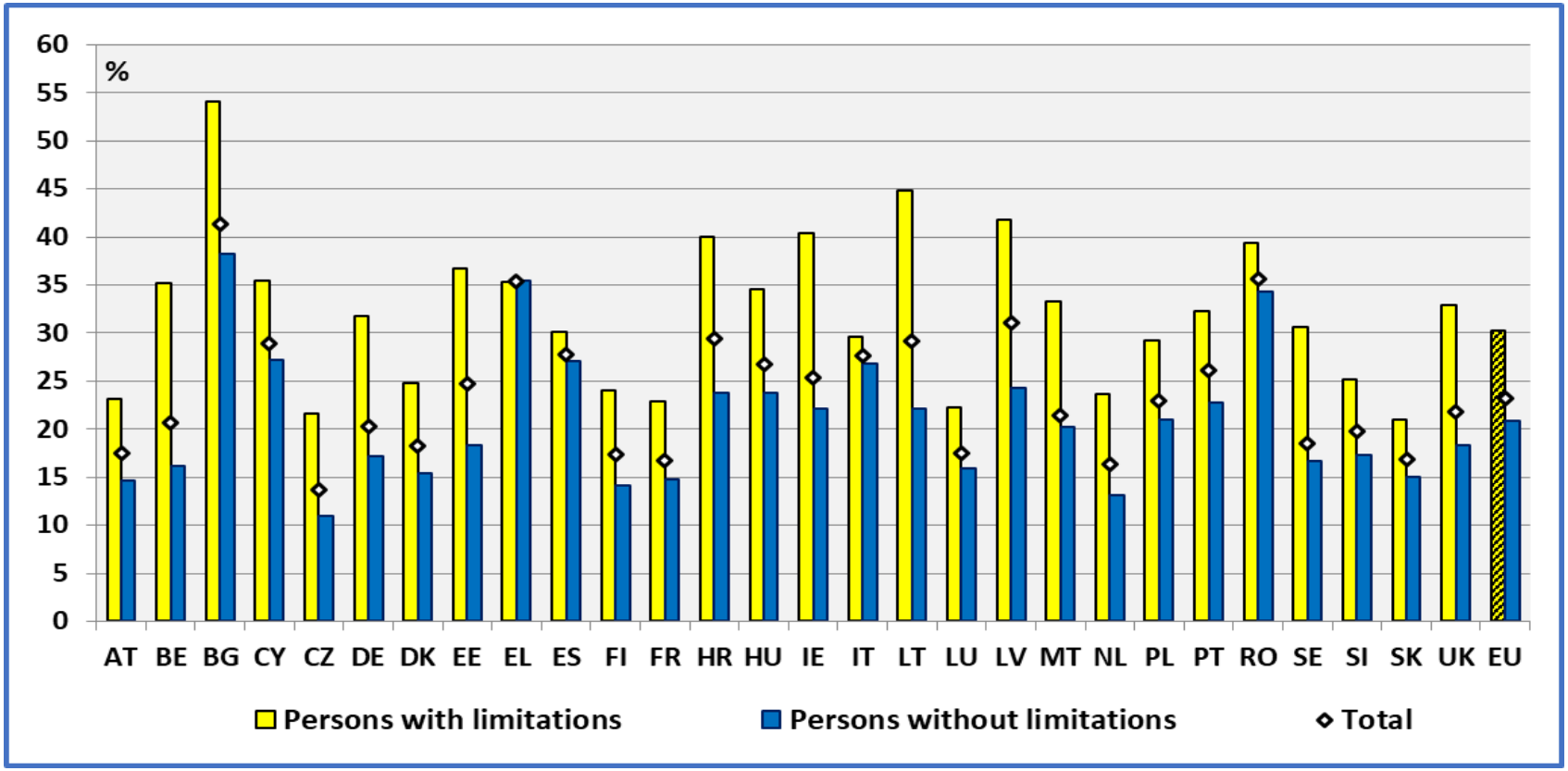


Disability related benefits shift the distribution curve towards higher relative incomes and reduce poverty of persons with disabilities by about 7 percentage points (EU-SILC 2013)

CESEP

PEOPLE AT-RISK-OF-POVERTY OR SOCIAL EXCLUSION

About 30.2% of people with disabilities are at risk of poverty or social exclusion compared to 20.8% of people without disabilities, in the EU (2015, Age: 16+)

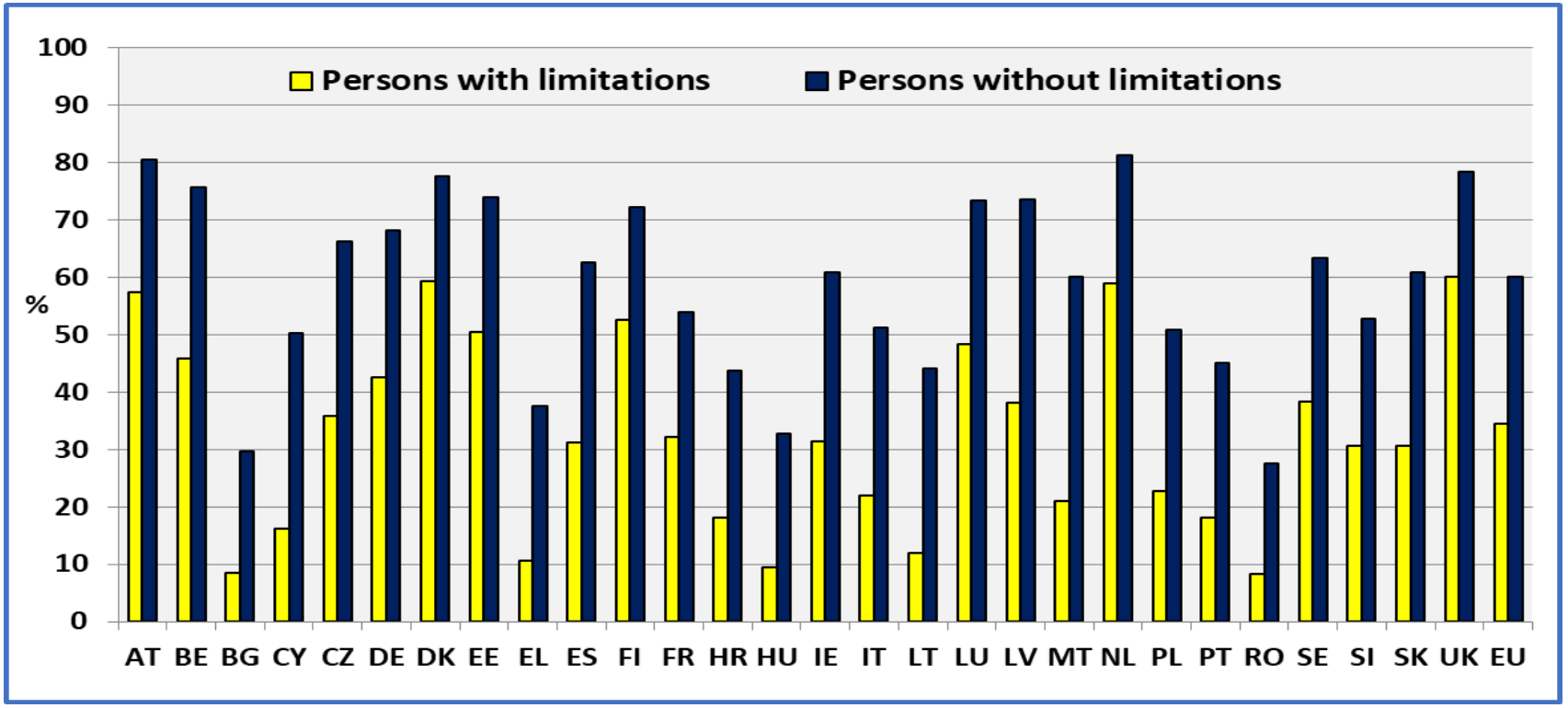


Bulgaria (54.1%), Lithuania (44.8%) and Latvia (41.8%) report the highest rates among persons with disabilities. Slovakia (21.0%), Czech Republic (21.6) and Luxembourg (22.3%) report the lowest rates among persons with disabilities (EU-SILC 2015).

EU-SILC UDB 2015

OTHER INDICATORS: PARTICIPATION IN LEISURE ACTIVITIES

Persons who regularly participate in a leisure activity (Age: 16+)
The considered activity(ies) such as sport, cinema, concert, etc. should occur outside home



EU: About 60% of persons without disabilities regularly participate in a leisure activity compared to 34% of persons with disabilities (EU-SILC MODULE 2015 ON SOCIAL/CULTURAL PARTICIPATION).
These differences might reveal barriers to participation. But we could not exclude health and health related risks. This indicator was included in the new 13 material/social deprivation items of EU2020.

EU-SILC UDB 2015 Module

MAIN FUTURE MONITORING INSTRUMENTS

1. INDICATORS FOR MONITORING THE SUSTAINABLE DEVELOPMENT GOALS (SDGS) IN AN EU CONTEXT

At the UN Sustainable Development Summit held in September 2015: the World leaders adopted the document "**Transforming our world: the 2030 Agenda for Sustainable Development**".
The document includes a list of:

- **17** Sustainable Development Goals (SDGs) and
- **169** targets which the subscribing national governments committed to pursue.

The **EU SDG indicator set** is structured along the 17 SDGs and includes **100 different indicators**.
SDGs include indicators of interest to people with disabilities, notably those covering Poverty, Health, Education, Gender equality, Economy & Labour, Inequality, Cities, Institutions.

2. EUROPEAN PILLAR OF SOCIAL RIGHTS: Social Scoreboard

1. Equal opportunities and access to the labour market (5 areas)
2. Dynamic labour markets and fair working conditions (3)
3. Public support / Social protection and inclusion (4)

It is important to disaggregate these indicators for persons with and without disabilities in order to monitor the evolution of any gap/disadvantage of persons with disabilities.

Source: Commission documents

center for inclusive policy

Disability assessment in the light of the UNCRPD

EU DISABILITY LAW AND THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

SEMINAR FOR NATIONAL CIVIL SERVANTS AND NGO STAFF

Alex.Cote

Triers, 1st October 2018

This publication has been produced with the financial support of the European Union's REC Programme 2014-2020. The contents of this publication are the sole responsibility of the author and can in no way be taken to reflect the views of the European Commission.

- Unbundling concepts
- Why does it matter?
- What the CRPD says?
- Which driving factors and set up?
- Which assessment?
- Data and assessment
- Conclusion

Why do states need disability assessment(s)?

- Granting a disability status (the disability card)?
- Elgibility to a specific scheme?
- Assessing support needs?
- Assess capacity to work?
- Curtailing rights in guise of protection?

To assess the “capacity” to exercise right (not in line with CRPD)

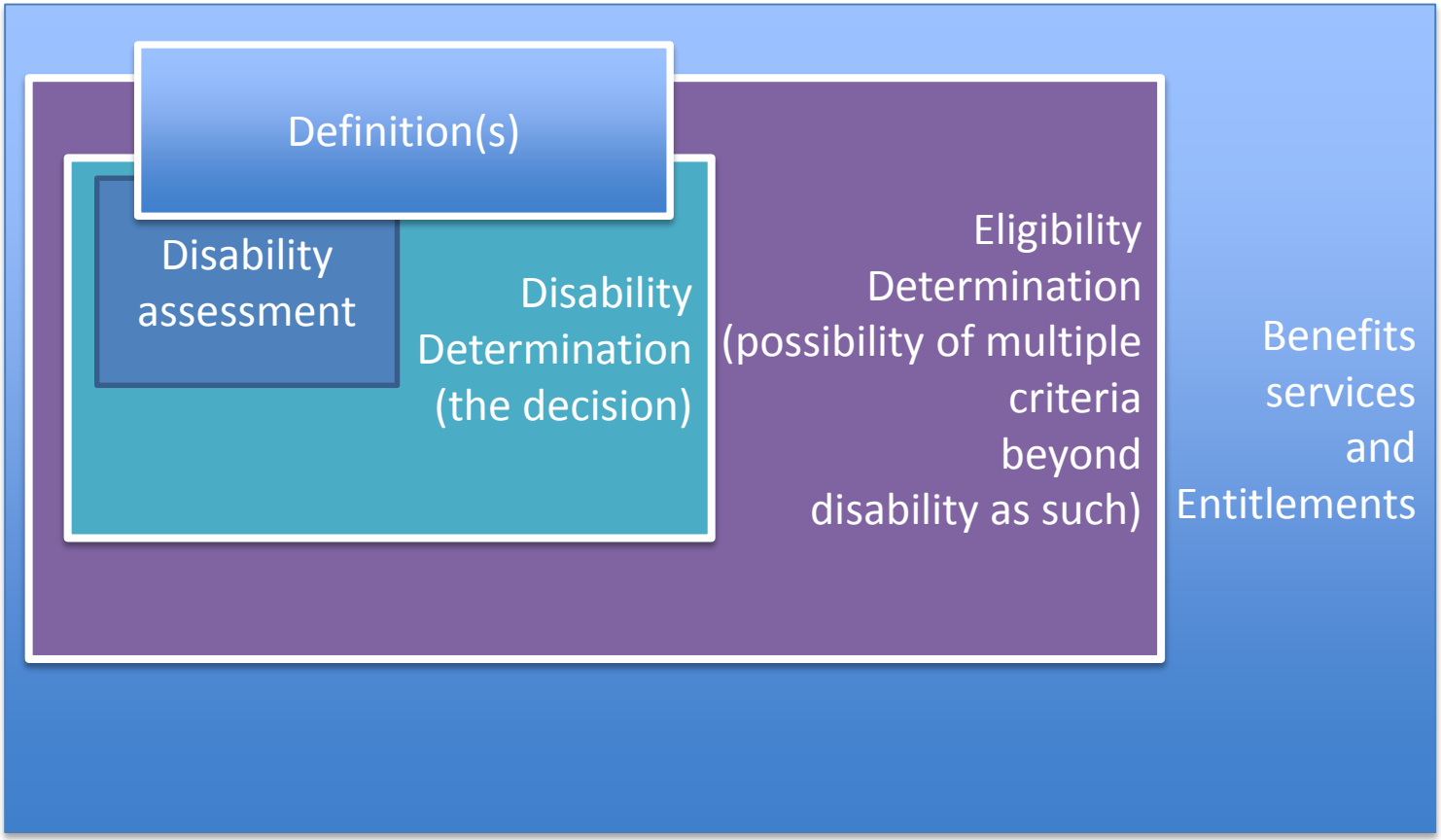
- “Mental capacity” assessment / functional test : could lead to deprivation of legal capacity, denial or right to decide for yourself, forced treatments…
- “IQ test” can lead to exclusion of children from mainstream or any form of education
- Work capacity assessment can contribute to further exclusion for labor market
- “Parenting” capacity in case of adoption..

UNBUNDLING DISABILITY ASSESSMENT, DISABILITY AND ELIGIBILITY DETERMINATION

”Definition(s)”

- Usually not one definition of disability in a country
- Link between the definition and the purpose of the policy/law articulating a given definition
- Describe who/what is covered by the law/policy/regulation
- The largest possible (anti-discrimination framework) - narrower (social protection oriented framework)

Unbundling



Legal disability definitions frame disability assessment and determination, but definition, assessment and determination are conceptually distinct as is overall eligibility determination.

Benefits and entitlements

- Income replacement benefits (Disability pension or allowance)
- Disability extra cost compensation (Independent living allowance)
- Assistive devices
- Health care services
- Personal assistance or …Residential care

- Relevance, adequacy, duration, periodicity of payment can be an issue

Eligibility determination

- It might include means test related criteria or others criteria
- It is the ultimate decision level in the process

- Disability and Eligibility determination criteria can evolved independently from the disability assessment

Disability determination

- Is the person considered a person with disability, under the legal definition of the relevant regulations, schemes and policies?
  - For the purpose of this act disability is defined as…
  - Most often those definitions are actually criterias and tresholds set the enable eligibility determination, they are not per se a definition of persons with disabilities or disability.
- It can lead to attribution of an official disability status which might give access to benefits and/or be one of the criteria of eligibility among others to access benefits and services.

Disability assessment

- It is the actual assessment
- It can focus on different elements:
  - The medical condition
  - The level of basic functioning (what people can or cannot do such mobility, hearing, seeing,…)
  - The capacity to work
  - The support requirement
  - The level of restriction of participation
  - The lost income
  - The cost of disability

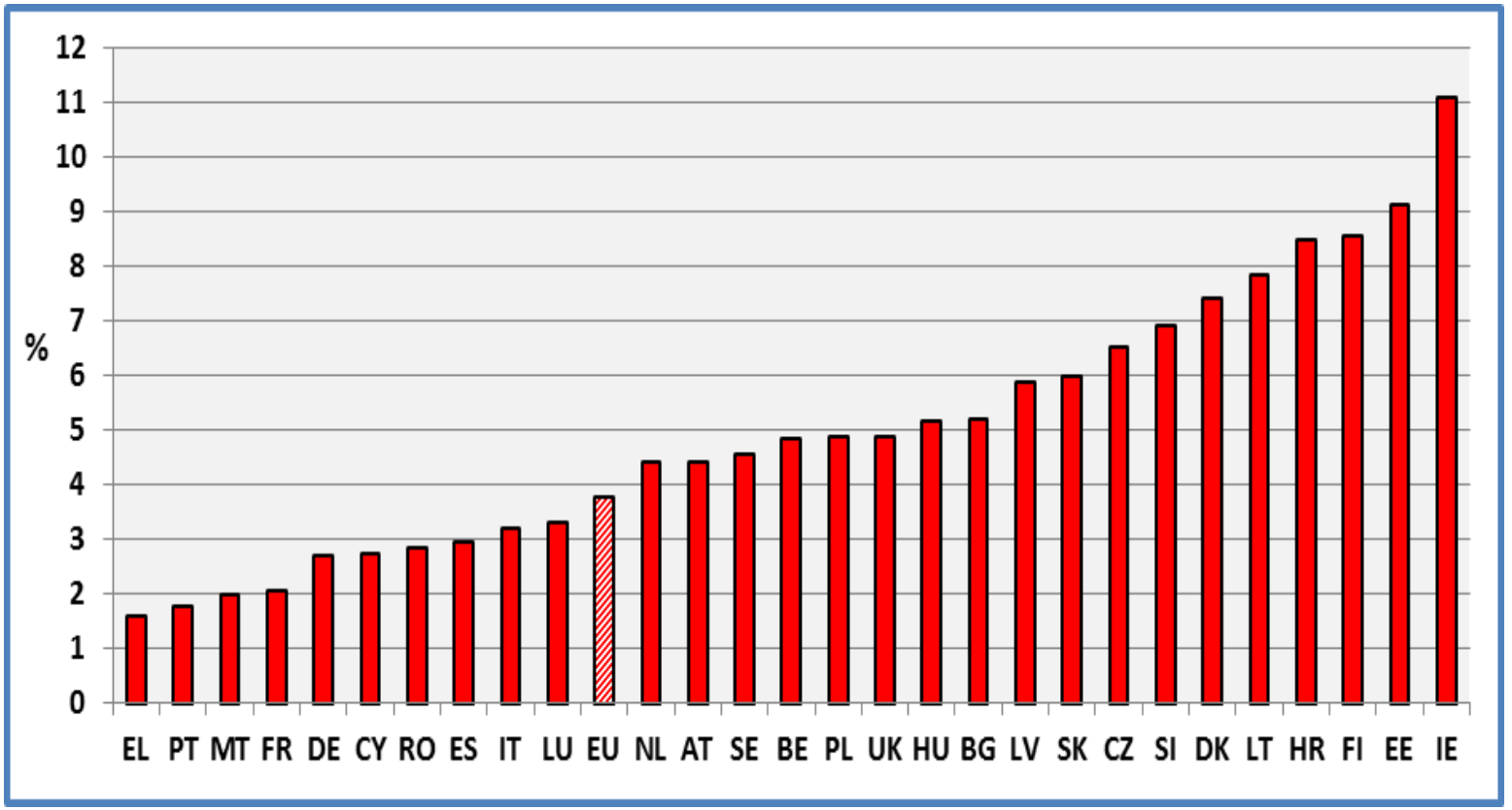
To which question(s) does it answer?

- What is the medical condition of the person?
- What is the impairment of the person?
- What is the person able to do?
- What is the person not able to do?
- What are the support needs of the person?
- What is the restriction of participation experience by the person?
- What are the barriers faced by the person?
- What would it take for the person to function equally?
- What would it take for the person to participate equally?

WHY DOES IT MATTER?

% of population recipient of disability benefits (16 years and above)

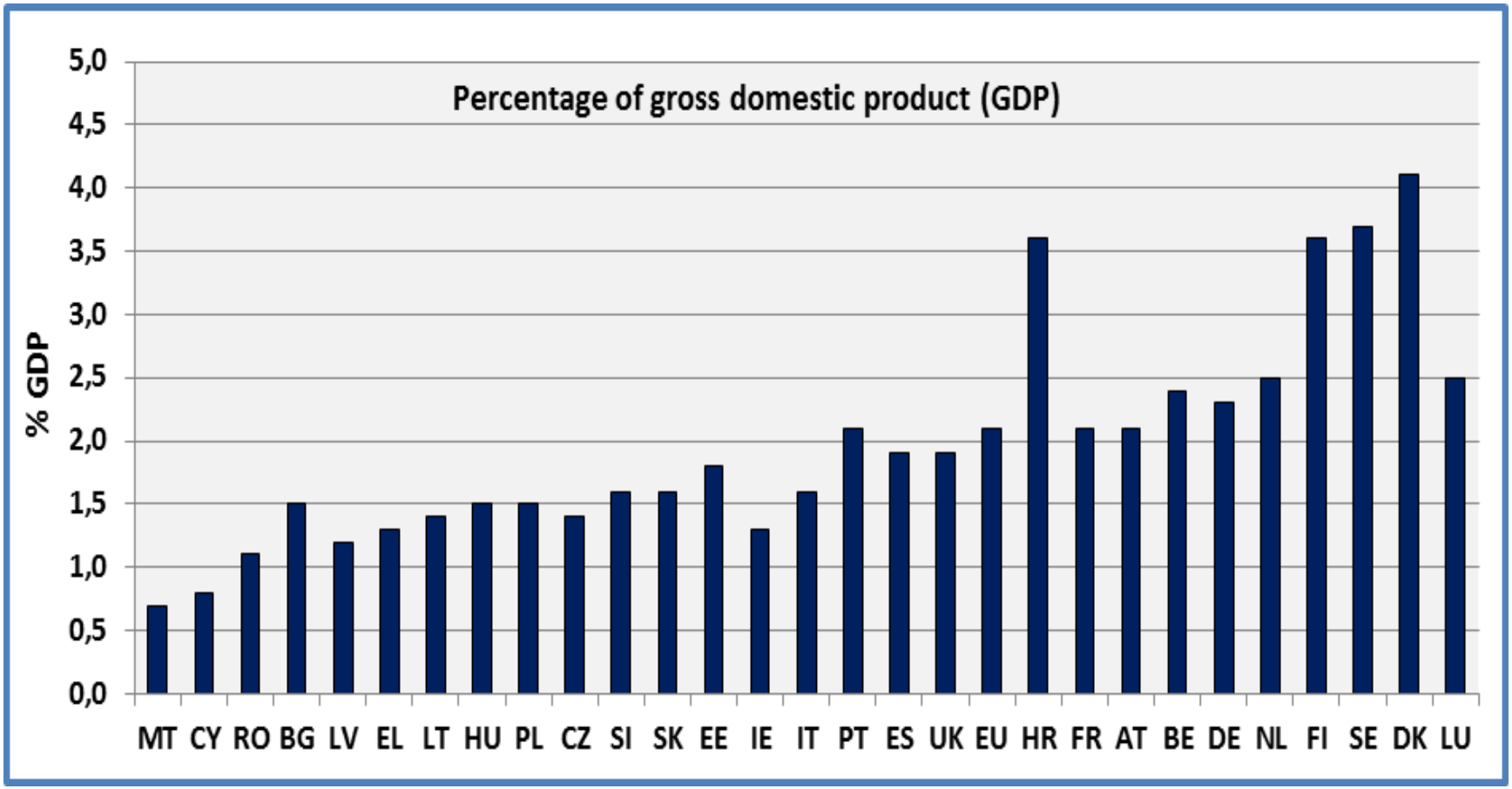
The share of the working age population on disability benefit in EU is 3.8% ranging from 1.6% in Estonia to 11% in Ireland.



Disability benefit as % of GDP in 2013

(Aned, 2017)

The average spending on disability benefit as a share of national GPD in EU is 2.1% ranging from 0.6% (Malta) to 4.1% (Denmark)



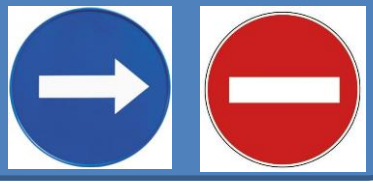
Critical and sensitive because…

PERSONS WITH DISABILITIES

POLICY MAKERS

DISABLED PEOPLE ORGANISATION

ELIGIBILITY PROCESS



ELIGIBILITY PROCESS
TARGETING AND RESOURCE ALLOCATION

ELIGIBILITY PROCESS
ENSURING ACCESS TO SUPPORT FOR THEIR MEMBERS

ENTITLEMENTS SUPPORT SERVICES AND BENEFIT

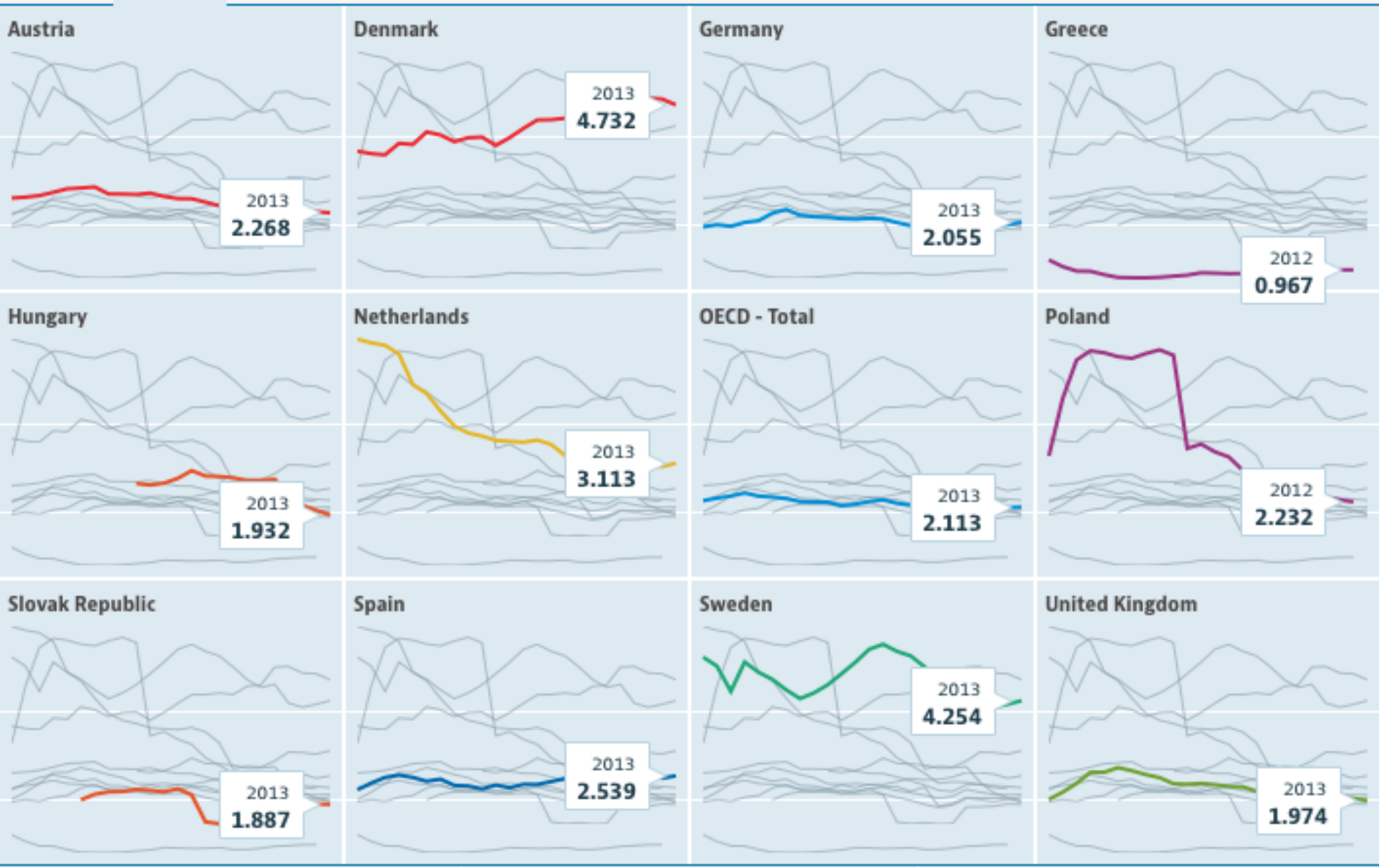
MANAGE AVAILABLE RESOURCES

LONG TERM SUSTAINABILITY

ONE OF THE MAIN TOOL TO IMPACT GOVERNMENT REOSURCES ALLOCATIONS

Public spending on “Incapacity” over time

(OECD database)



The credibility issue (Bickenbach and al, 2015)

- Rising number of complaints and appeal against decision with significant overruling as a results:
  - USA: More than 38 percent of awards to individuals who applied for Disability Insurance between 1997 and 2000 were made after an initial denial
  - In the UK a total of 142 complaints against the PIP assessment process in 2015/16 against 1391 in 2016/17. 40-50% of the complaints are upheld.
  - 1,287,323 Employment & Support Allowance (Work capabilities assessment) appeals, at least 567,634 decision overturned in their favour.

Views in EU about eligibility ... (Aned, 2017)

- ”Several country reports included criticisms of eligibility rules that effectively excluded some people with disability-related needs from financial and practical support, or created inequities by offering some groups preferential treatment. For example,
  - in Austria children and older people are excluded from receiving personal assistance as well as persons with intellectual, multiple or psychosocial disabilities.
  - Similarly in Croatia autistic people are not eligible for financial help for personal communication instruments.
  - Age discrimination was identified as a concern in Slovakia, Austria and the UK.
  - In the Germany report a concern was raised that eligibility/entitlement criteria are sometimes difficult to define (such as whether ‘essential requirement’ includes services and devices that support leisure activities) so that interpretations by caseworkers often lead to appeals in the case of rejected applications which are the case of stress and delay.”

… and assessment (ANED, 2017)

- Application and assessment procedures attracted a range of criticisms in a number of country reports. They were variously described as “
  - time-consuming, frustrating, exhausting and humiliating, particularly for people with mental health problems or intellectual disabilities (Austria, Sweden and Germany),
  - too bureaucratic (Portugal, Latvia, the Netherlands),
  - inflexible (Iceland) and invasive of people’s privacy (Sweden).
  - the complexity of procedures was a concern in Germany and Slovakia.
  - A linked criticism was that procedures took too long (Croatia, Ireland, Latvia, Portugal, the Czech Republic and Sweden).
  - In some countries there was criticism of the basis on which decisions were made, ie reflecting a medical model of disability (Cyprus, Iceland) and about the type of staff making decisions (Cyprus, Finland).

- In the Netherlands the country report commented positively about the large discretionary freedom given to municipalities to support disabled people with cash benefits, supports, and devices. This allowed municipalities to tailor support to an assessment of individual circumstances.”

WHAT THE CRPD SAYS?

Prescriptive or not?

- Preambule and art 1 insist on the **interaction** between **the persons with an impairment** and **barriers in the environment** hindering **participation**

- Art 26: mentioned multidisciplinary assessment of individual **needs and strengths** for habilitation and rehabilitation

- Art 12 mention a **review of support** provided to exercise legal capacity.

Elements of the CRPD committee jurisprudence

- Czeck Republic
  - The Committee calls upon the State party to amend the definitions of disability and persons with disabilities in its legislation and to make explicit reference to the barriers faced by persons with disabilities in the above-mentioned definitions, in order to harmonize them with the definitions in the Convention.
- Portugal
  - The Committee recommends that the State party review the assessment criteria to determine the degree of disability of the individual to bring them into line with the Convention, and adopts suitable regulations in its legislation and policies. The Committee also recommends that the State party ensures that all persons with disabilities are able to secure their disability certificate, and that access to social protection programmes and aid is available to all persons with disabilities.
- Serbia
  - The Committee recommends that the State party review its legislation, including assessment of disability and support schemes, and harmonize it with the Convention, including the human rights model of disability. (…) It further recommends the State party to review the assessment of working capacity to eliminate the medicalised approach and to promote the inclusion of persons with disabilities in the open labour market.
- Slovakia
  - The Committee recommends that the State party adopt a human rights-based definition of disability in the regulations relating to the assessment of disability.

Elements of the CRPD committee jurisprudence

- Korea:
  - The Committee recommends that the State party review the current disability determination and rating system under the Welfare of Disabled Persons Act to ensure that the assessment reflects the characteristics, circumstances and needs of persons with disabilities(…)
- Sweden
  - it is also concerned about families with disabilities being subjected to additional investigations, carried out by local authorities and social services in the framework of the national adoption system, to assess their parenting ability. (…)The Committee recommends that the State party ensure the prohibition of discrimination on the basis of disability in adoption procedures.
- Croatia
  - It further recommends that benefits aiming at alleviating increased costs arising from disability should be based on an assessment of the individual's support needs, and should disregard any financial assets test.
- Bolivia
  - The Committee recommends that the State party amend the criteria for certification of disability to reflect the social, human rights-based model of disability, and that it make the procedure accessible, simple and free of charge for all persons with disabilities.

General comment art 19

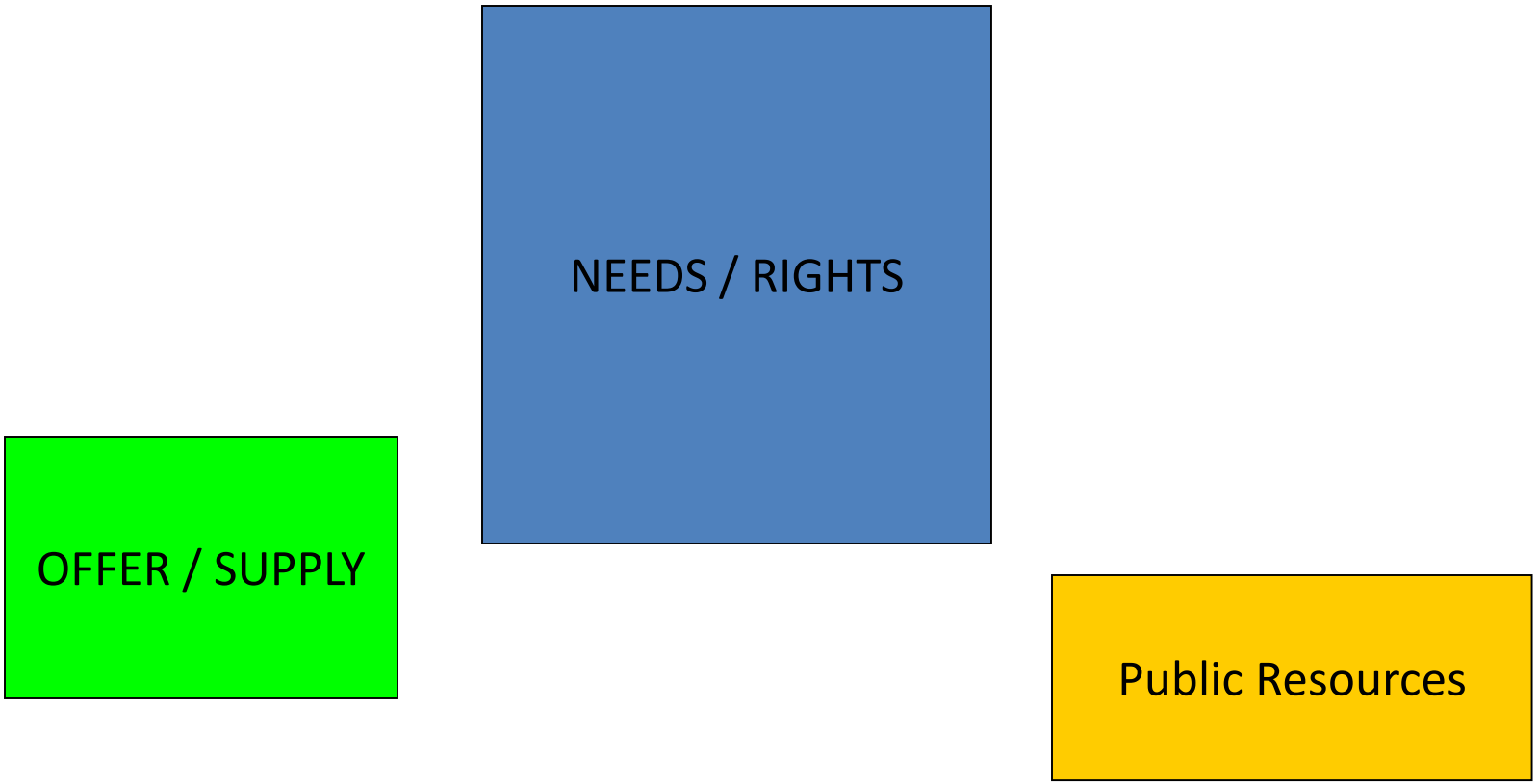
- "The assessment should be based on *a human rights approach to disability*, focus on *the requirements of the person because of barriers within society rather than the impairment*, take into account, and follow a person's will and preferences, and ensure the full involvement of persons with disabilities in the decision-making process."
- Support for persons with disabilities should be assessed, through a personalised approach, and tailored to the specific activities and actual barriers that persons with disabilities face in being included in the community.
- The assessment should acknowledge that persons with disabilities require access to participate in activities that are varying over time.

Moving away from (in)capacity to work assessment

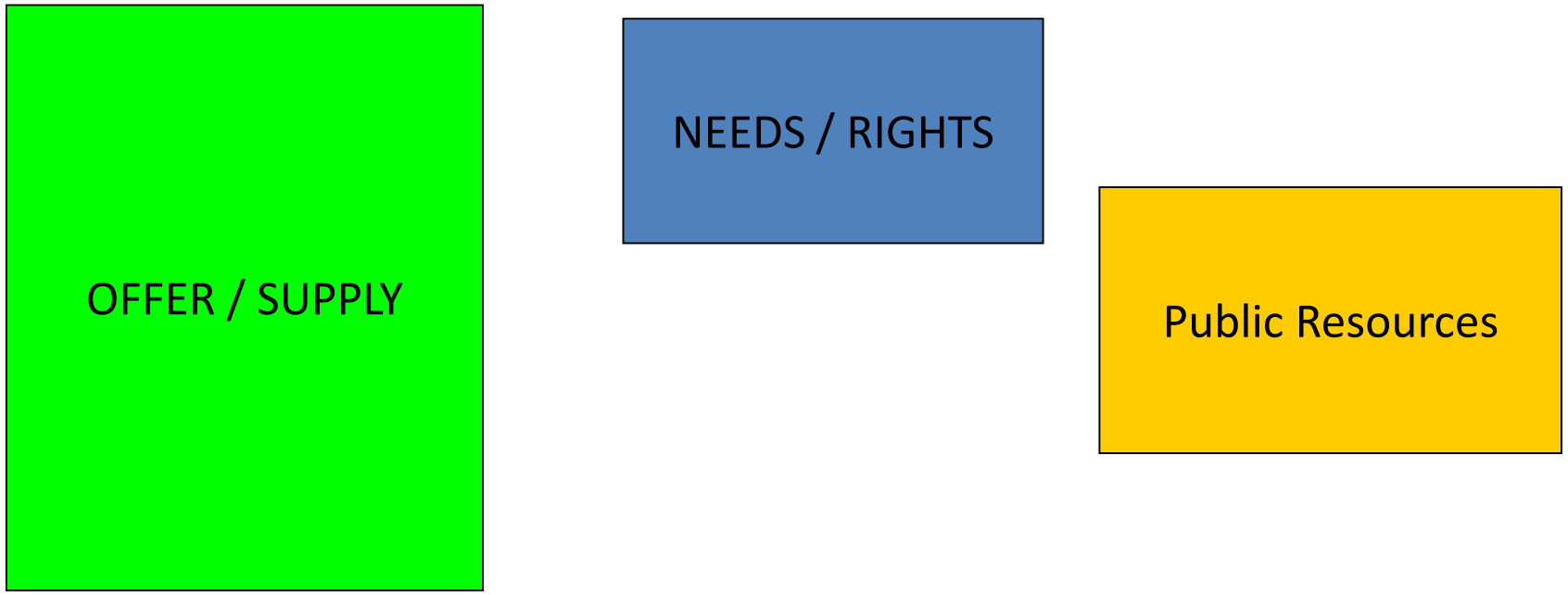
- There is a need to explore further how best to articulate the rational for income security/support while not disqualifying and dis-incentivizing individuals and without losing legitimacy and political/popular buy-in
- Building on the return to work approach without ignoring the barriers and discrimination in the labor market:
  - Shift from “one cannot work” to “one is not in position to work due to barriers and lack of support in the work environment”
  - Accept the fact that welfare conditionality do little for workforce integration - UK Welfare conditionality research (Dwyer,2018)

WHICH DRIVING FACTORS?

Needs/rights driven ? = waiting list and pressure on policy maker + creation of new services



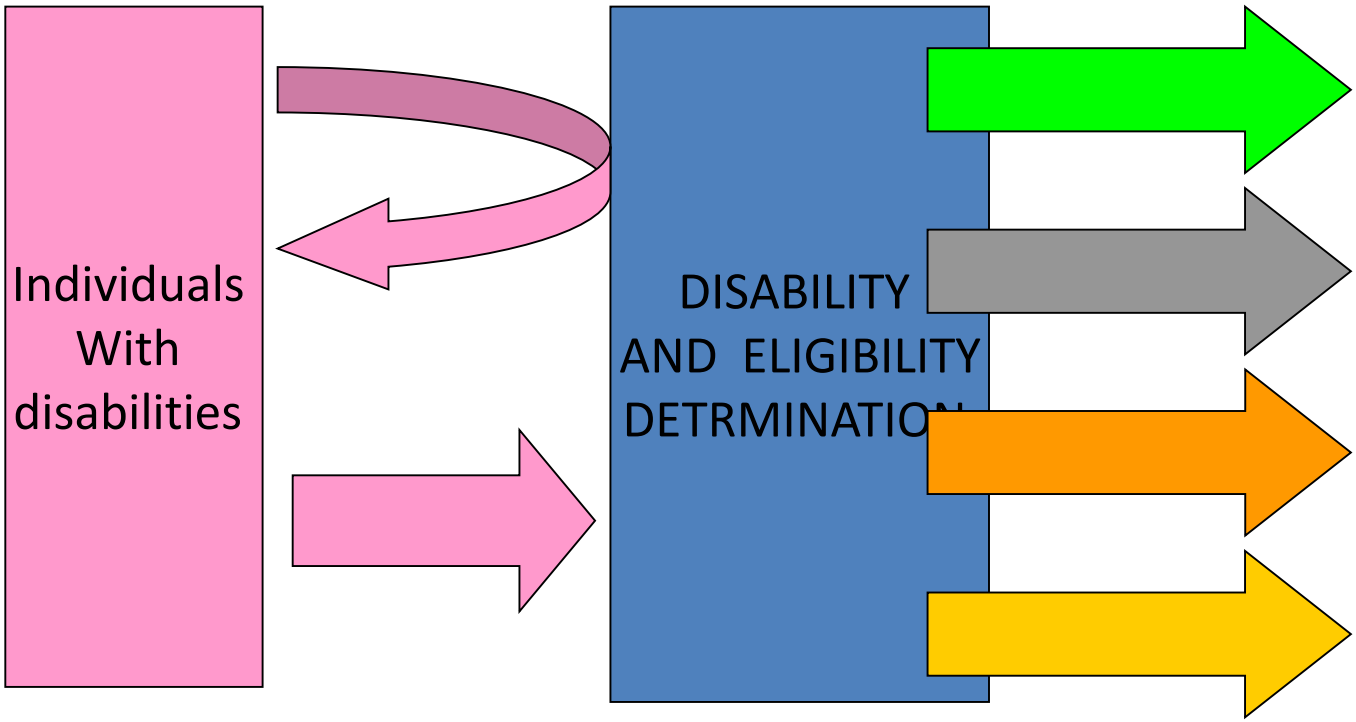
Supply driven? = waiting list but biaised assesment as there is a lack of diversity



Resources driven: the fake perfect match?= no waiting list as state entitle as much as it can afford

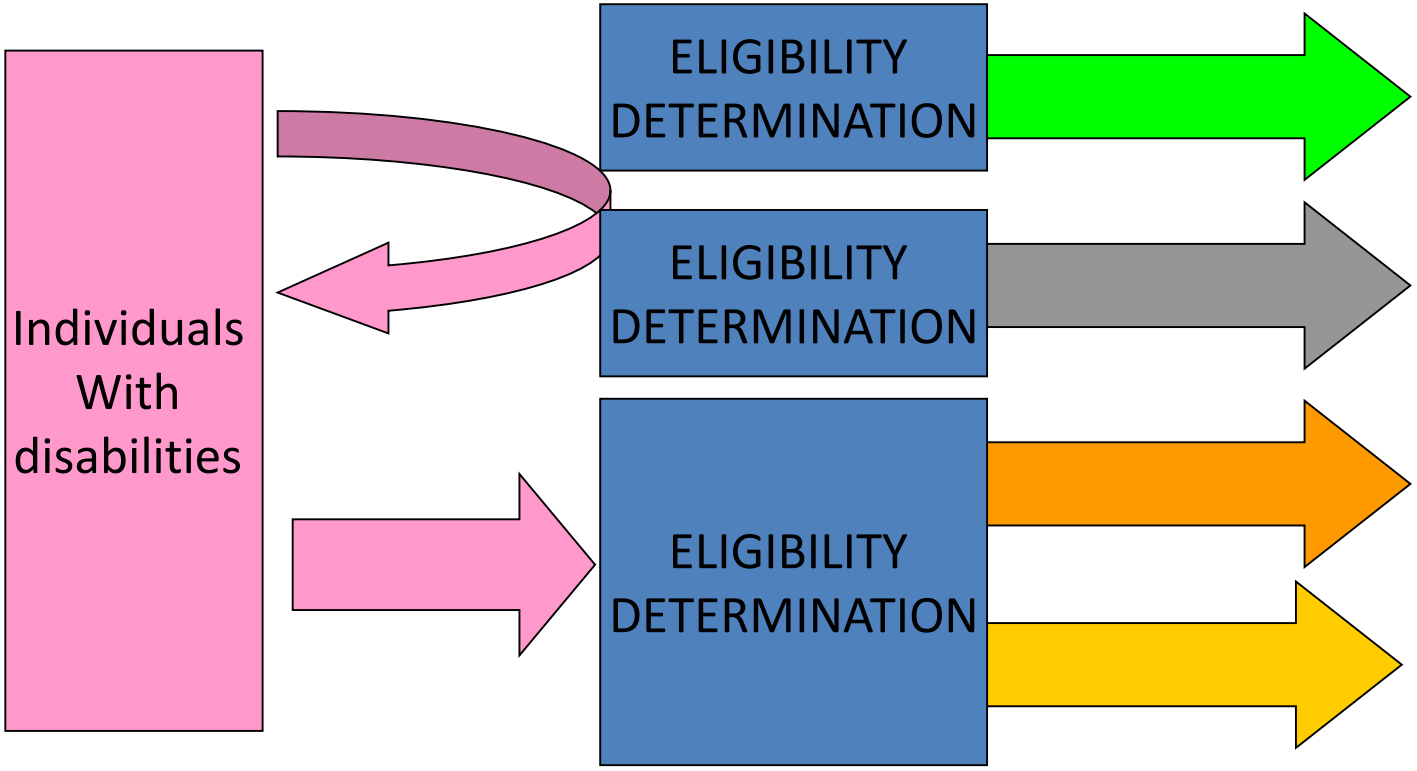
WHICH SET UP?

“ONE STOP SHOP”



In this approach, a single disability and eligibility determination process give access to different benefits

Not “ONE STOP SHOP”

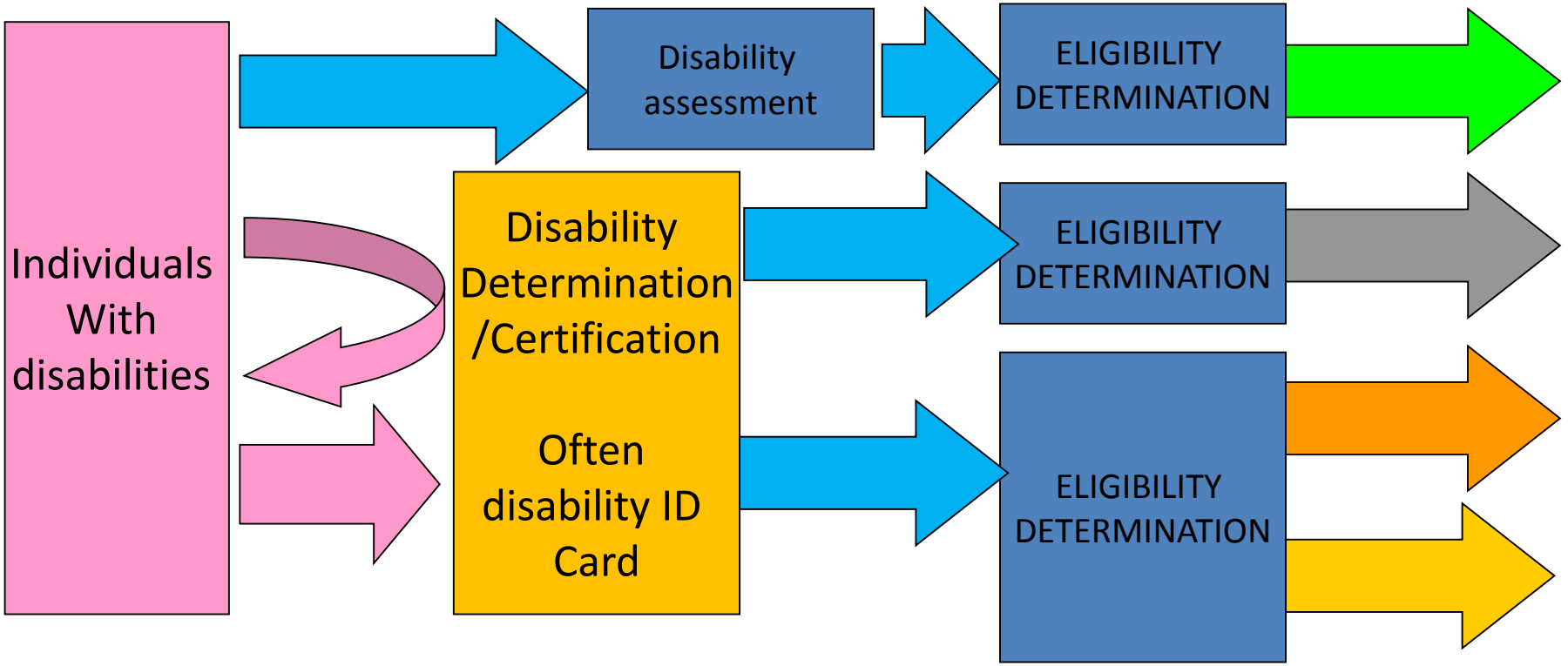


In this approach different benefits and services have their own disability and eligibility determination process

Pro and cons

	PRO	CONS
One stop shop	Simplicity and less administrative burden for persons with disabilities and their families Streamlined bureaucracy	If rejected in this process, little opportunity to get support Could lead to less ownership on inclusion by respective ministries
Multiple entry points	If rejected from one process, individuals still have the possibility to be accepted in another. Trigger greater ownership by ministries suppose to deliver services if they have their own eligibility process	Heavy process for persons with disabilities and their families Costs associated with multiple processes Competing “definition” and complexity for persons with disabilities

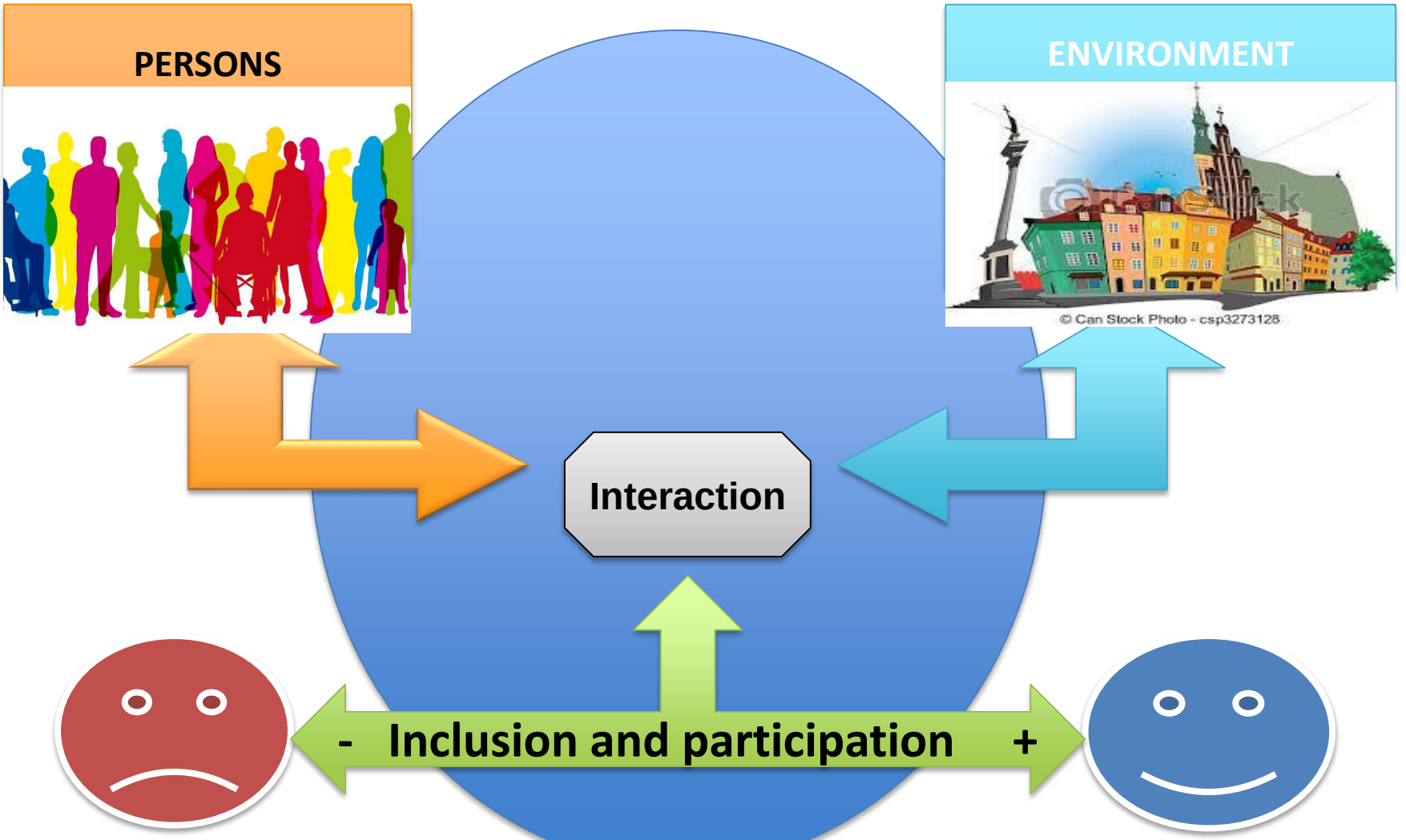
A mix approach

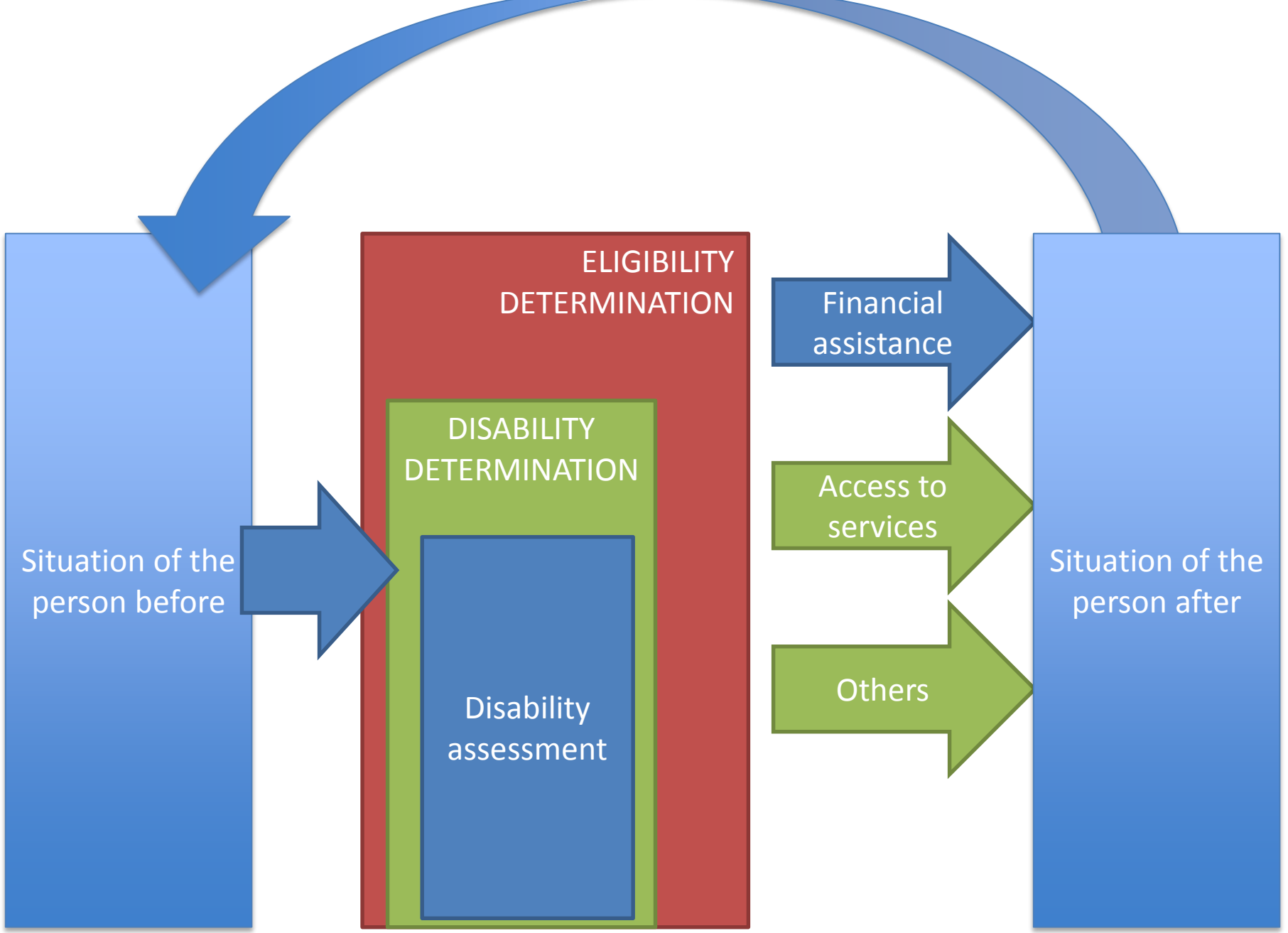


In this approach, there is a main disability certification which become part of the different eligibility determination processes

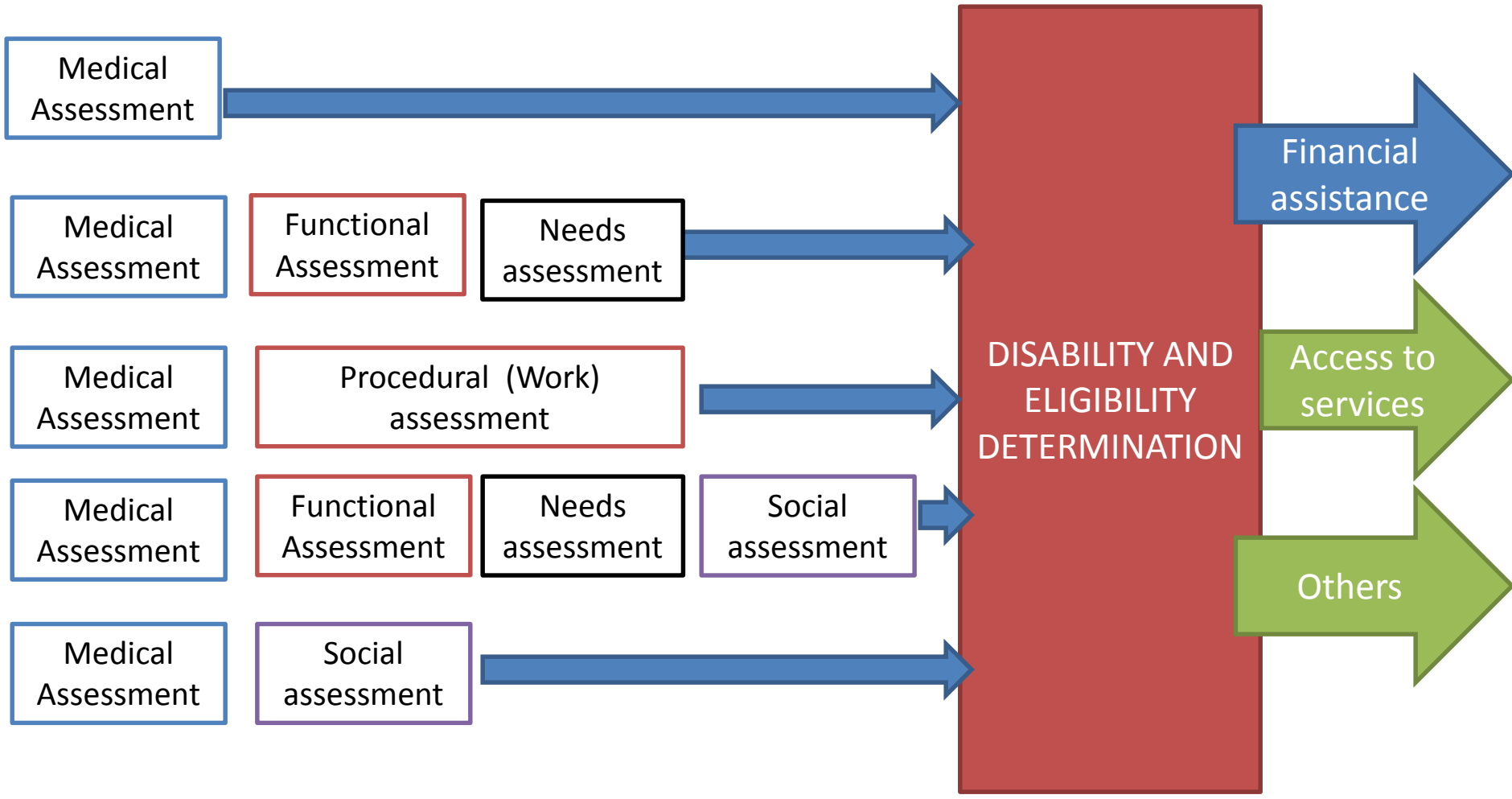
WHICH ASSESSMENT?

What is assessed?

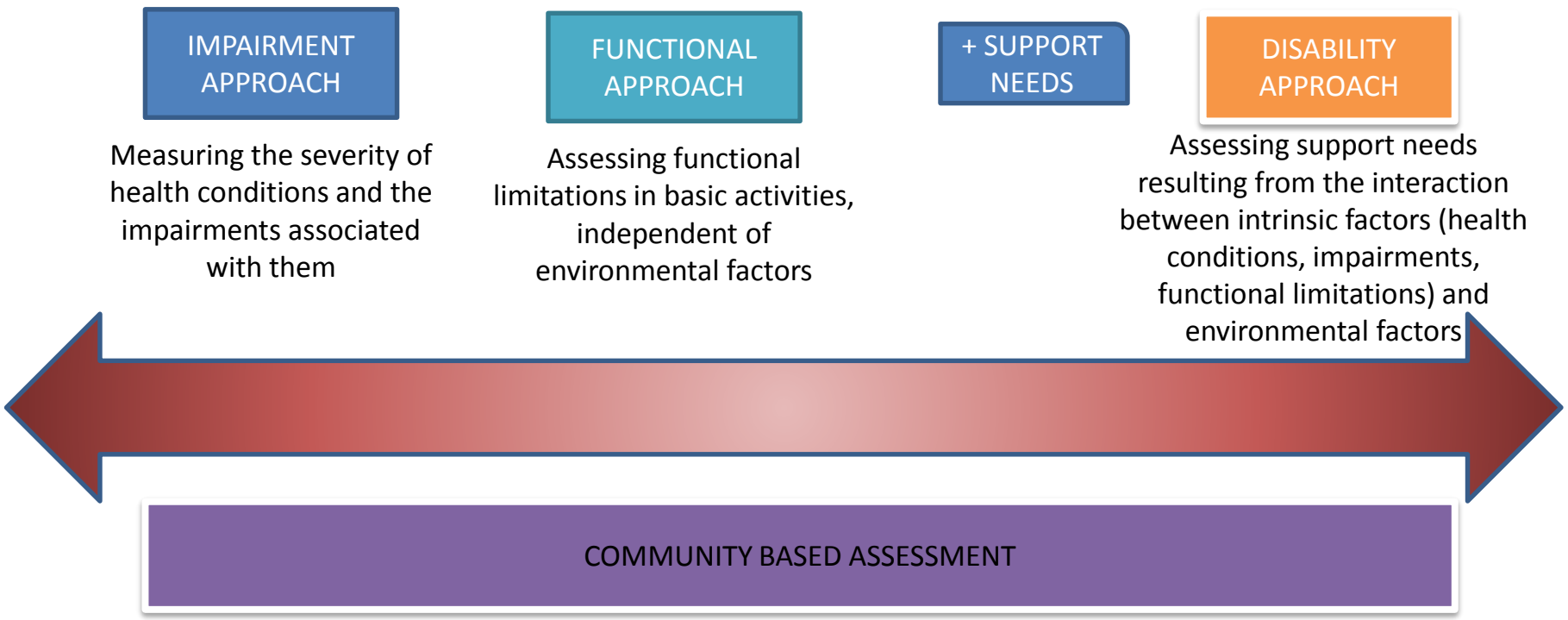



Situation of the person before
ELIGIBILITY DETERMINATION
DISABILITY DETERMINATION
Disability assessment
Financial assistance
Access to services
Others
Situation of the person after

Different scenarios



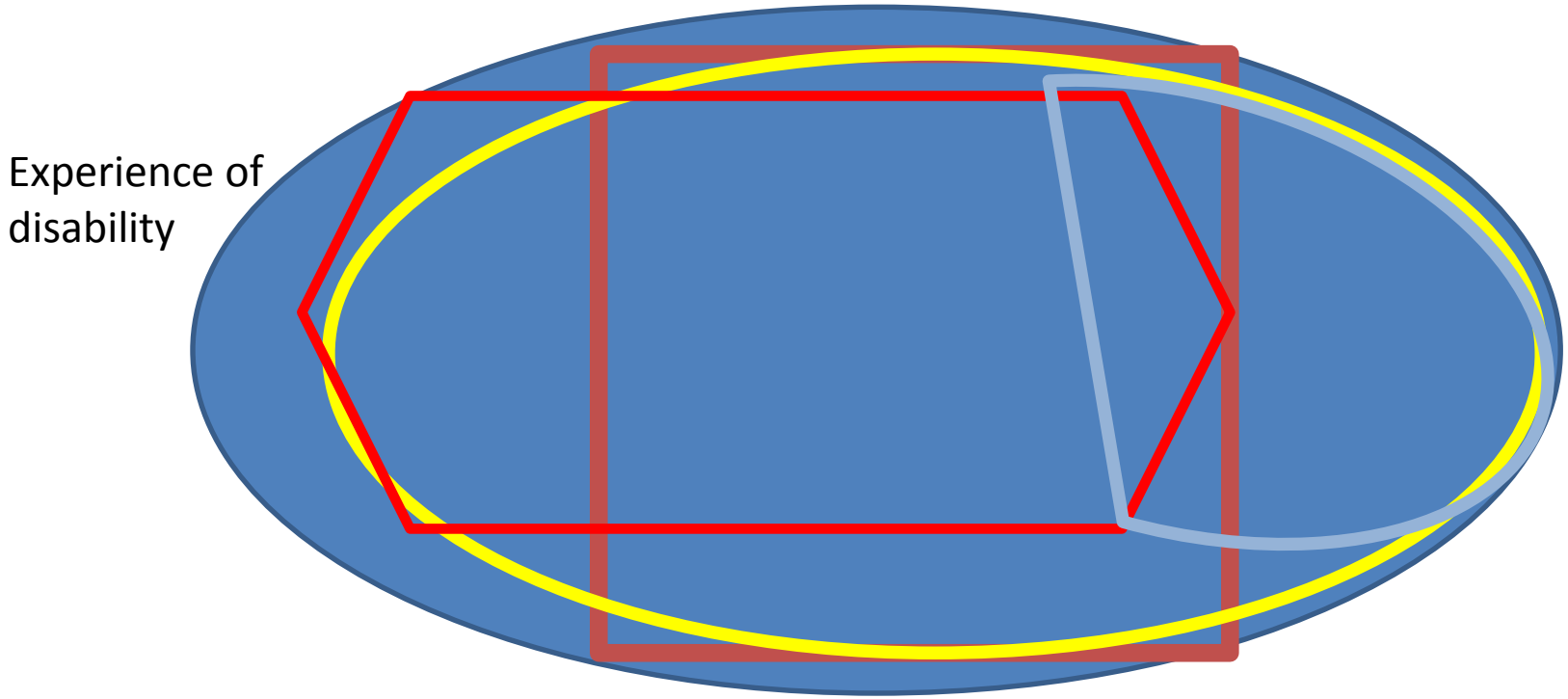
Which Disability Assessment?



What is assessed? (Bickenbach, 2015)

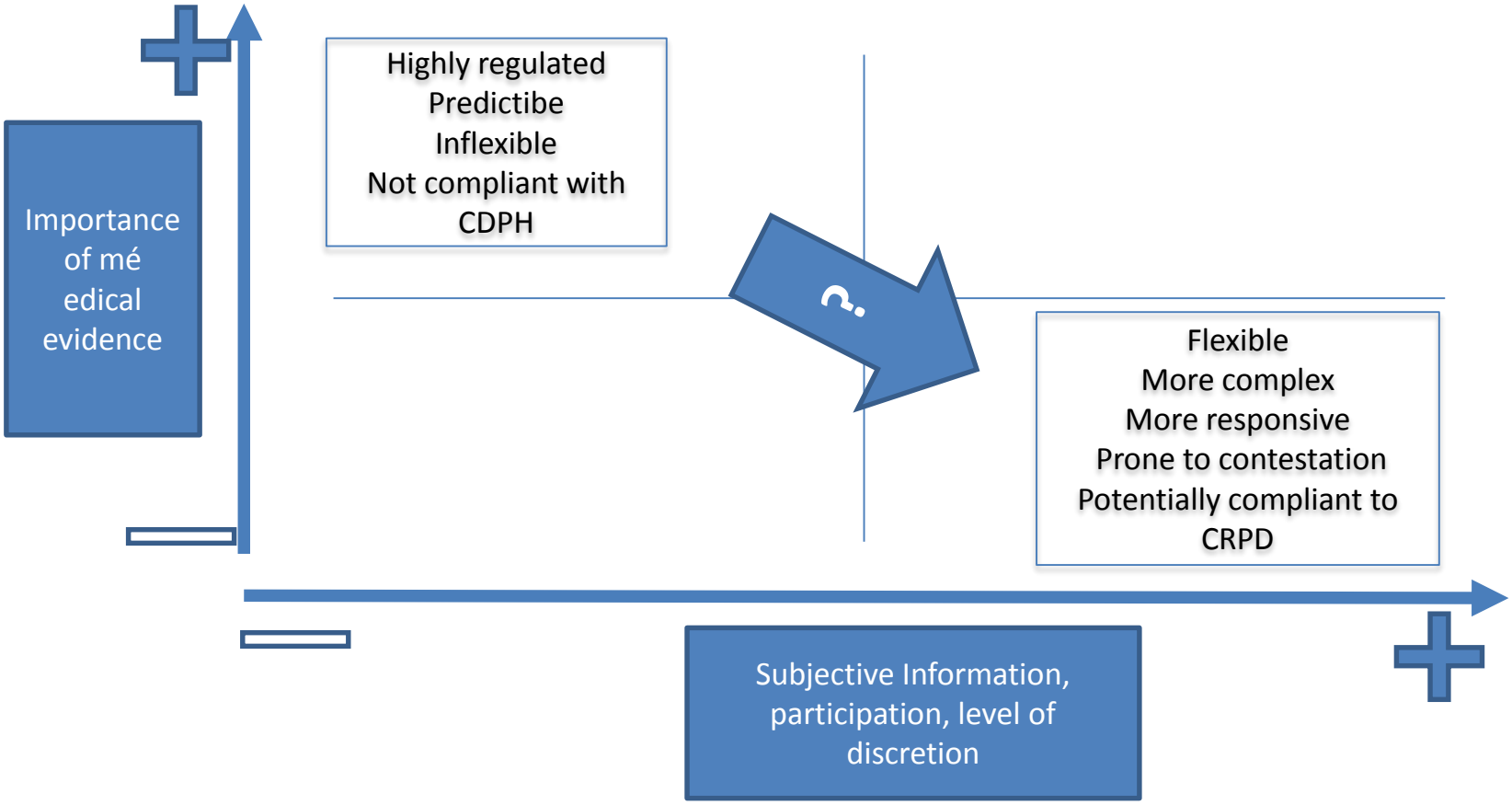
Approach	Conception of 'disability'	Standardize tool or guideline	Criteria
IMPAIRMENT	**Medical** Health state (injury, disease or syndrome), Plus problems with body functions and structures	**Impairment guidelines:** *AMA Guidelines for the Evaluation of Permanent Impairments* (6th ed.)	**'Baremas' criteria**: Presence of problem at the body level as indirect indicator of 'whole person' or disability rating
FUNCTIONAL	**Functional** Problems or limitations in basic activities	**Functional Capacity Evaluations (FCE):** *Functional Status Questionnaire* *Disability Assessment Structured Interview* *Work Ability Index, etc.*	**ADL/IADL criteria**: Presence of a problem or limitation in basic activity as indirect indicator of disability rating
DISABILTY	**Disability** Disability is the outcome of an interaction of health condition and environmental factors at the body, person and societal levels	**Disability Assessment:** WHODAS2[lvii] ICF Checklist[lviii] ICF Core Sets[lix]	**Bio-psycho-social criteria:** Description of kind and severity of disability as an outcome of interaction between an individual's health and functional capacity and environmental factors

Assessment is always a (very) partial description of reality

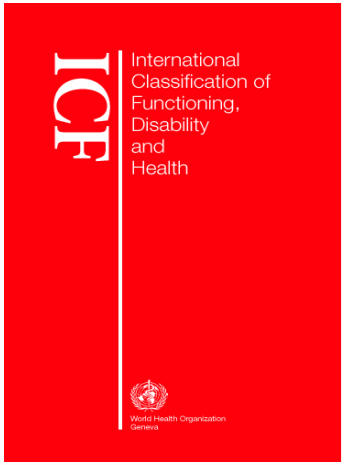


What contributes to the decision?

(based on Kidd, 2017 based on on Bolderson et al (2002)



International Classification of Functioning, Disability and Health



Health Condition
(disorder/disease)

Body function and structure
(Impairment)

Activities
(Limitation)

Participation
(Restriction)

Environmental Factors

Personal Factors

ICF related Definitions

Impairment	Loss or abnormality in body structure or function (including mental function)
Activity Limitations	Difficulties individual may have in executing activities in terms of quantity or quality
Participation Restrictions	Problems an individual may experience in involvement in life situations
Facilitators & Barriers	Environmental factors may be a facilitator for one person & barrier for another

The incapacity, capacity, support requirements?

- The person can’t…
- The person can...
- The person can only if ....
- In absolute
- In his/her environment ?

Which sources of information?

- Medical certificate from usual GP or specialist
- Medical history
- Self report
- Semi directed interview

Who is doing the assessment?

- Doctor
- Multidisciplinary teams
- Social worker

General comment art 19 (repeat)

- "The assessment should be based on *a human rights approach to disability*, focus on *the requirements of the person because of barriers within society rather than the impairment*, take into account, and follow a person's will and preferences, and ensure the full involvement of persons with disabilities in the decision-making process."
- Support for persons with disabilities should be assessed, through a personalised approach, and tailored to the specific activities and actual barriers that persons with disabilities face in being included in the community.
- The assessment should acknowledge that persons with disabilities require access to participate in activities that are varying over time.

Trends in EU

- Many countries are reviewing their disability assessment due to tow elements: austerity and CRPD compliance
- All countries have medical assessment as a more or less preeminent part of the disability assessment and determination process
- Most countries include functional assessment and in some cases support (care) needs.

ASSESSMENT AND DATA

Further data collection

- Are the data collected for disability and eligibility determination used for policy planning and monitoring.
  - What are the support needs of people?
  - Who is currently accessing support? Assistive devices?
  - What is the challenges faced by children, women, adult, and elderly people?

CONCLUSION

Issues to consider

Unbundling

- Benefits
- Eligibility criteria
- Disability determination
- Disability assessment

Issues …

Legal

- What is the legal definition of disability related to the determination and assessment?
- Which legal framework govern the assessment?
- Appeal possibilities?

Technical:

- What is the classification used ?
- Who are the staff involved / needed for the assessment?
- Which professional and information weight the most in decision
- Information system

Access

- How easy is the process? Availability, accessibility, affordability, quality

Issues…

Political stakes

- For DPOs :
  - accessing support and
  - controlling the sharing of resources
- For professional and institutions:
  - resistance to change, loss and gains…
- For government
  - delivering support and
  - controlling expenditures
  - Avoiding fraud..

CRPD compliant disability assessment

- An assessment that is CRPD-compliant should respect the following principles:
  - Respecting the dignity of the person
  - Full accessibility (information, meetings, etc..)
  - Having been designed with the participation of representative DPOs
  - Country-wide coverage (proactive outreach strategy) and particular attention to those most in disadvantage (rural, remote, etc..)
  - Respecting the diversity of disability
  - Include assessment of support requirement and barriers
  - Respect for privacy (of data)
  - Gender-sensitive and respectful of indigenous people
  - Involved DPOs
- Ramp to access support
- Should never be used to restrict recognition or exercise of rights
- Should not be used for anti discrimination case
- Making disability assessment processes CRPD compliant is part of the obligations of States Parties

Assessing the procedure with CRPD

(Arnould and al, 2012; Castelein and al 2017)

Art.5 Is the assessment procedure non discriminatory on the basis of disability, sex, sexual orientation, religious or ethnic origin?
Art.5 Is there sufficient guarantee for reasonable accommodation in the assessment procedure?
Art.6 Does the procedure respect the autonomy and dignity of women and girls with disabilities?
Art.7 Is the procedure adapted to the specific needs of the child ? Does the assessment procedure allow the child to express his or her opinion?
Art. 9 Is the disability determination procedure accessible to any person with a disability (physical, information, communication, etc.)?
Art. 12 Does the disability determination procedure support the exercise of legal capacity?
Art. 21 Can the person with disability consult his / her file to exercise his right to freedom of expression and opinion by accessing understandable information and using his/her preferred means of communication?
Art.22 Does the procedure guarantee the protection of privacy and the confidentiality of information?
Art. 31 Are the privacy and confidentiality of the collection of private data (use of individual files, etc.) guaranteed?

Some element of consensus…

- Disability determination
  - Should be CRPD compliant
  - is not disability prevalence
  - Should not be use to curtail rights
  - Should not contribute to prejudice
  - Is not required for protection against discrimination
  - Include assessment of support requirement and barriers
  - Include DPOs in design and monitoring
  - Should have appeal procedure
  - Should be simple enough for clarity and transparency purpose

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L'évaluation du handicap à la lumière de la CDPH

DROIT DE L'UE RELATIF AUX HANDICAP ET CONVENTION DES NATIONS UNIES RELATIVE AUX DROITS DES PERSONNES HANDICAPÉES (CDPH)

SÉMINAIRE POUR LES FONCTIONNAIRES NATIONAUX ET LE PERSONNEL DES ONG

Alex.Cote

Triers, 1 Octobre 2018

Cette publication a été réalisée avec le soutien financier du programme de l'UE « Droits, égalité et citoyenneté » (2014-2020). Les vues exprimées n'engagent que l'auteur et ne reflètent pas nécessairement celles de la Commission Européenne.

Structure

- Differencier les concepts
- En quoi est-ce important?
- Que dit la CDPH?
- Quels sont facteurs guidant la réforme?
- Quelle évaluation?
- Données et évaluation
- Conclusion

Pourquoi une évaluation du handicap?

- Accorder un statut de personnes handicapés (la carte handicp)?
- Admissibilité à un dispositif spécifique?
- Evaluer les besoins de support?
- Evaluer la capacité à travailler?
- Limiter les droits sous prétexte de protection?

Point clefs: évaluer la capacité à exercer un droit (non conforme à la CDPH)

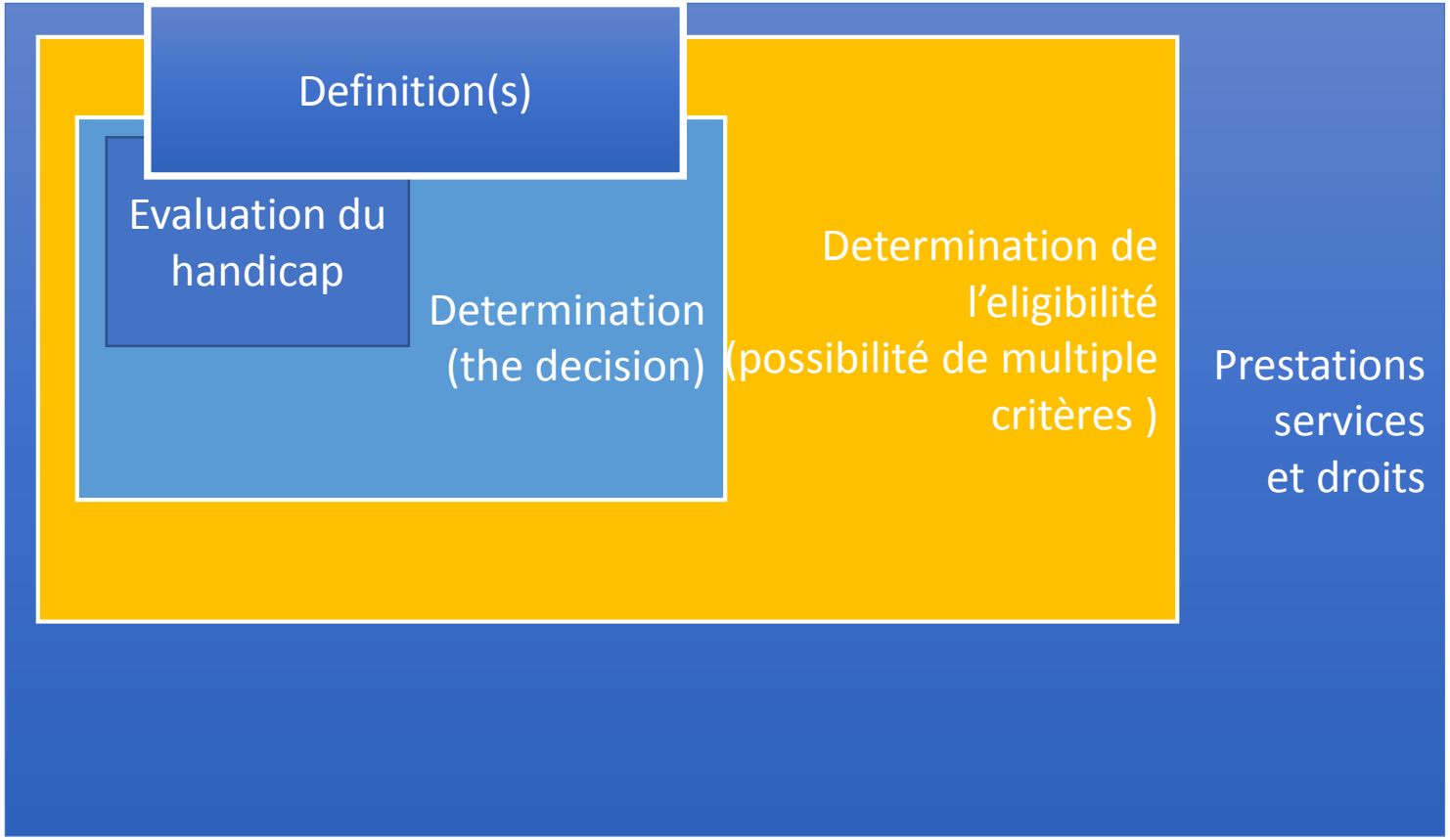
- Évaluation «capacité mentale» / test fonctionnel: peut entraîner la privation/limitation de la personnalité juridique et capacité d'agir en droit , le déni ou le droit de décider par soi-même, les traitements forcés…
- Le «test de QI» peut conduire à exclure les enfants de l'enseignement général ou de toute forme d'éducation
- L'évaluation de la capacité de travail peut contribuer à une plus grande exclusion du marché du travail
- Capacité «Parentale» en cas d'adoption.

Differencier évaluation, détermination et éligibilité

Definition(s)

- Généralement pas une définition du handicap dans un pays
- Lien entre la définition et le but de la politique / loi articulant une définition donnée
- Décrit qui / ce qui est couvert par la loi / politique / réglementation
- La plus large possible (cadre anti-discrimination) - plus restreinte (cadre axé sur la protection sociale)

Diffèrencier les concepts souvent melés en réalité



- Les définitions légales du handicap influencent l'évaluation et la détermination, mais la définition, l'évaluation et la détermination sont distinctes sur le plan conceptuel, tout comme l'éligibilité en général

Prestations et services

- Prestations de remplacement du revenu (pension handicap ou allocation)
- Allocation pour frais supplémentaires du handicap (allocation de vie autonome)
- Dispositifs d'assistance
- Services de santé
- Assistance personnelle ou… Soins résidentiels
- La pertinence, l'adéquation, la durée, la périodicité du paiement peuvent poser problème

Eligibilité

- Cela peut inclure des critères relatifs aux ressources ou autres
- C'est le niveau de décision ultime dans le processus
- Les critères de détermination du handicap et de l’éligibilité peuvent évoluer indépendamment de l'évaluation du handicap

Détermination du handicap

- La personne est-elle considérée comme une personne handicapée au sens de la définition légale des réglementations, régimes et politiques concernés?
  - Aux fins de cette loi, le handicap est définie comme suit…
  - Le plus souvent, ces définitions sont en réalité des critères et des seuils définissant la détermination de l'admissibilité, elles ne constituent pas en soi une définition des personnes handicapées ou du handicap.
- Cela peut conduire à l'attribution d'un statut officiel de personne handicapée qui donne accès à des prestations et / ou être l'un des critères d'admissibilité parmi d'autres pour accéder aux prestations et aux services.

L’évaluation du handicap

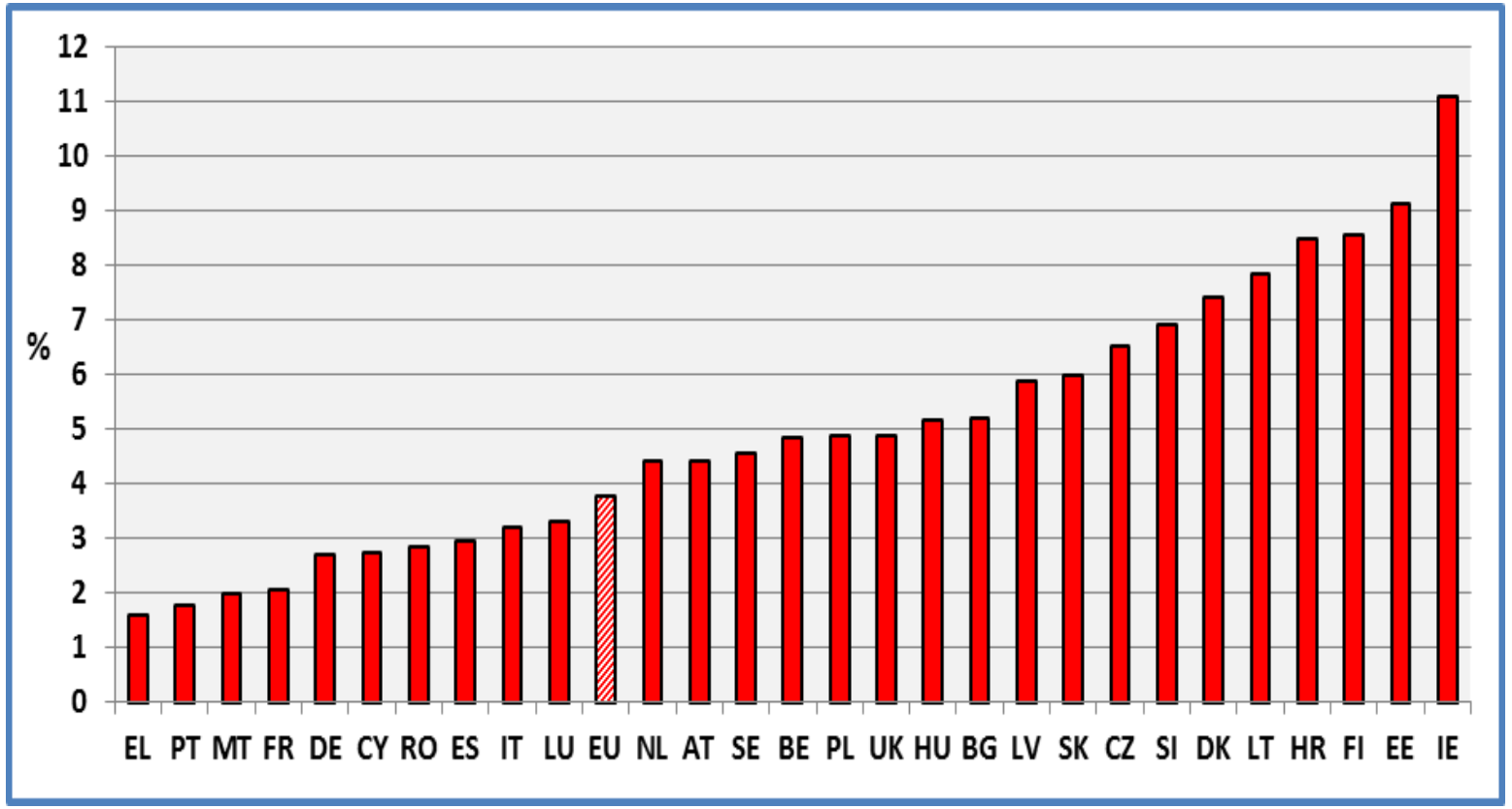
- C'est l'évaluation à proprement parler
- Elle peut se concentrer sur différents éléments:
  - La condition médicale
  - Le niveau de fonctionnement de base (ce que les gens peuvent ou ne peuvent pas faire en terme de mobilité, activités de la vie quotidienne…)
  - La capacité de travailler
  - Le besoin de soutien
  - Le niveau de restriction de participation
  - Le revenu perdu
  - Le coût du handicap

A quelle(s) question(s) repond-elle?

- Quelle est la condition médicale de la personne?
- Quelle est la déficience de la personne?
- Qu'est-ce que la personne est capable de faire?
- Qu'est-ce que la personne n'est pas capable de faire?
- Quels sont les besoins de soutien de la personne?
- Quelle est la restriction de participation de la personne?
- Quels sont les obstacles rencontrés par la personne?
- Que faudrait-il pour que la personne fonctionne de manière équivalente ?
- Que faudrait-il pour que la personne participe de manière équivalente?

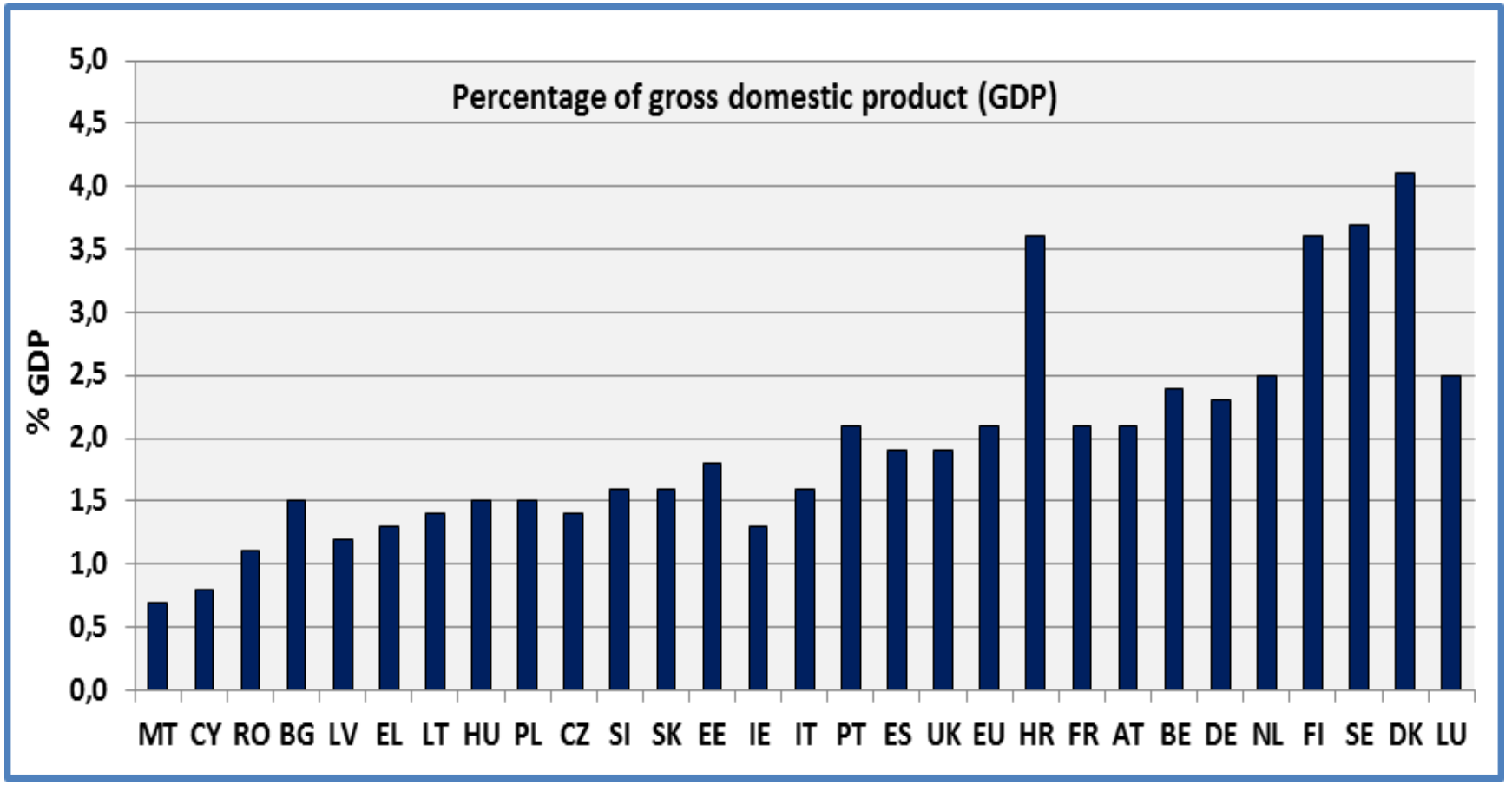
Pourquoi est-ce important?

% de la population bénéficiant d'une allocation handicap en Europe



- La part de la population en âge de travailler qui bénéficie de prestations du handicap dans l'UE est de 3,8%, allant de 1,6% en Estonie à 11% en Irlande.

% du PIB pour les allocations handicap



- Les dépenses moyennes en prestations du handicap en pourcentage du PIB national dans l'UE sont de 2,1%, allant de 0,6% (Malte) à 4,1% (Danemark).

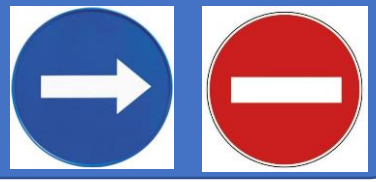
Critique and sensible …

PERSONNES HANDICAPEES

DECIDEURS POLITIQUES

ORGANISATIONS DE PERSONNES HANDICAPEES

ELIGIBILITE



ELIGIBILITE

CIBLAGE DES AIDES

EVITER LA FRAUDE

ELIGIBILITE
ASSURER L' ACCES DE LEUR MEMBRES AUX PRESTATIONS

SOUTIEN SERVICES ALLOCATION

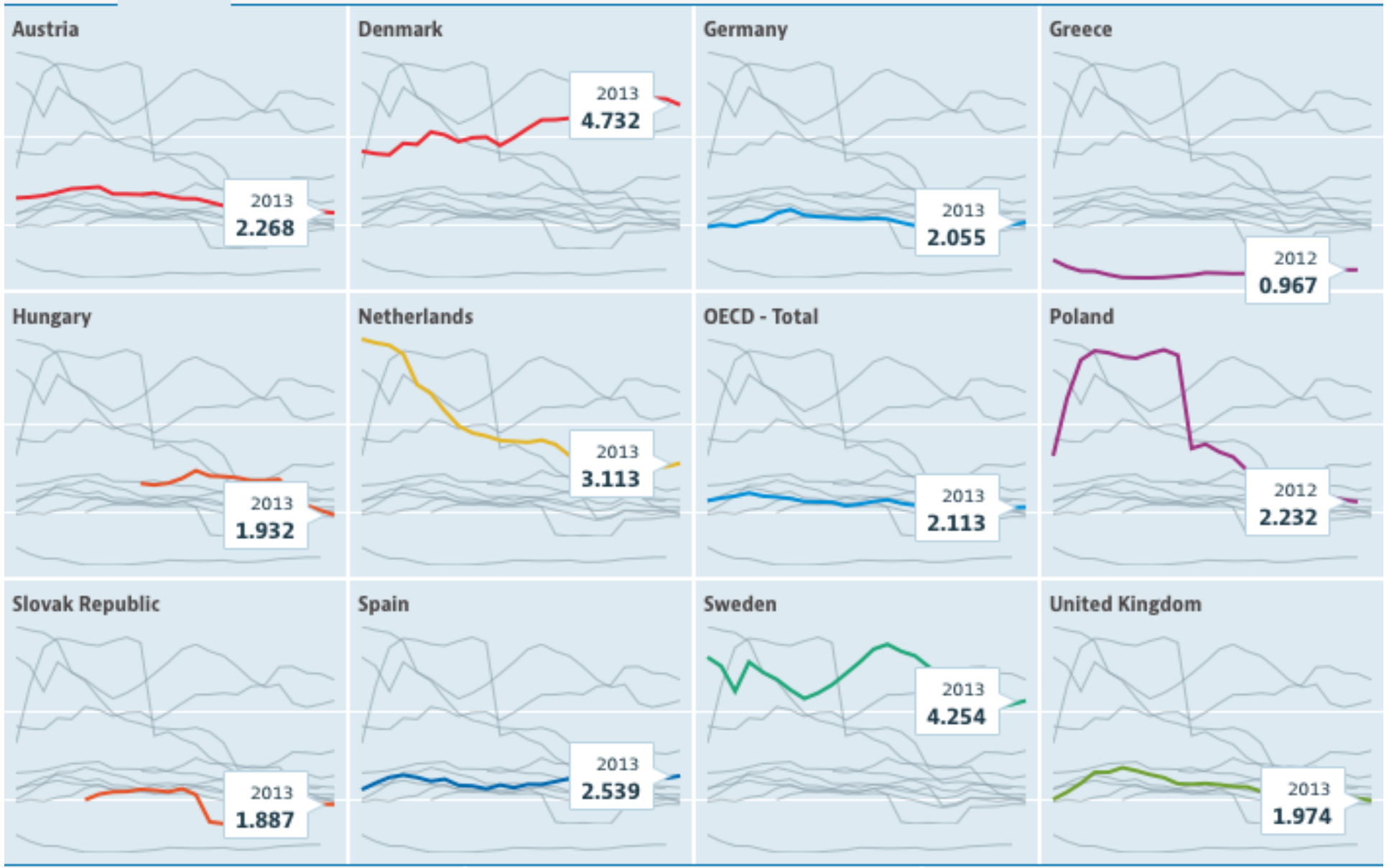
GESTION DES RESSOURCES

VIABLITE A LONG TERME

UN DES OUTILS PRINCIPAUX POUR INFLUENCER LES ALLOCATIONS DE RESSOURCES

Dépenses publiques pour l’“Incapacité” dans le temps

(OECD database)



La question de la crédibilité

- Augmentation du nombre de plaintes et appel de la décision avec un rejet important des décisions initiales:
  - États-Unis: plus de 38% des accords aux personnes ayant demandé une allocation handicap entre 1997 et 2000 ont été accordées après un refus initial
  - Au Royaume-Uni, un total de 142 plaintes contre le processus d'évaluation du PIP en 2015/16 contre 1391 en 2016/17. 40 à 50% des plaintes sont confirmées.
  - 1 287 323 appels relatifs à l'indemnité d'emploi et de soutien (évaluation des capacités de travail), au moins 567 634 décisions ont été annulées en leur faveur des plaintifs.

Vue sur l’éligibilité… (Aned 2017)

- “(…) critiques sur les règles d'éligibilité qui excluaient dans les faits certaines personnes ayant des besoins, liés au handicap, en terme de soutien financier et pratique, ou créaient des inégalités en offrant à certains groupes un traitement préférentiel. Par exemple,
  - en Autriche, les enfants et les personnes âgées sont exclus de l'assistance personnelle ainsi que des personnes présentant des handicaps intellectuels, multiples ou psychosociaux.
  - De même, en Croatie, les personnes autistes ne sont pas éligibles à une aide financière pour les instruments de communication personnels.
  - La discrimination fondée sur l'âge a été identifiée comme une préoccupation en Slovaquie, en Autriche et au Royaume-Uni.
  - Selon le rapport de l’Allemagne, les critères d’éligibilité / d’admissibilité sont parfois difficiles à définir (par exemple, les «besoins essentiels» comprennent-ils les services et les appareillages liées aux activités de loisir?) ce qui impliquent que les intrepretations diverses des personels en charge aboutissesnt à des appels qui sont source de stress et de retard.

Et l’évaluation du handicap

- Les procédures d'évaluation ont suscité diverses critiques dans un certain nombre de rapports nationaux.
  - Ils ont été diversement décrits comme «consommateur de temps, frustrant, épuisant et humiliant, en particulier pour les personnes ayant des problèmes de santé mentale ou une déficience intellectuelle (Autriche, Suède et Allemagne),
  - Trop bureaucratique (Portugal, Lettonie, Pays-Bas),
  - Inflexible (Islande) et envahissent la vie privée (Suède).
  - la complexité des procédures était une préoccupation en Allemagne et en Slovaquie.
  - Une critique connexe était que les procédures prenaient trop de temps (Croatie, Irlande, Lettonie, Portugal, République tchèque et Suède).
  - Dans certains pays, la base sur laquelle les décisions étaient prises, à savoir refléter un modèle médical du handicap (Chypre, Islande) et le type de décisions prises par le personnel (Chypre, Finlande).
- Aux Pays-Bas, le rapport national a formulé des commentaires positifs sur la discretion laissé aux municipalités dans la decisions liées à l’accès des personnes handicapées à aux allocations, aides et autres dispositifs. Cela a permis aux municipalités d'adapter le soutien sur la base d’une évaluation des circonstances individuelles. "

Que dit la CDPH?

Elle n’est pas spécifique ni prescriptive

- Préambule et art 1 insistent sur l'interaction entre les personnes ayant une déficience et les obstacles dans l'environnement qui entravent la participation
- Art 26: évaluation multidisciplinaire mentionnée des besoins individuels et des points forts pour l'adaptation et la réadaptation
- L’article 12 mentionne un examen de l’appui fourni pour exercer la capacité juridique.

La jurisprudence du comité CDPH est plus claire

- L’évaluation du handicap doit:
  - Etre en conformité avec la CDPH
  - Adopte le modèle basé sur les droits humains du handicap et evite l’approche médicale
  - Reflète les caractéristiques, circonstances et besoins des personnes handicapées
  - Évaluer les besoins de soutien
  - Une procédure simple, accessible à toutes les personnes handicapées et gratuite
  - …

Observation générale sur l’article 19

- l’évaluation devrait reposer sur une approche du handicap fondée sur les droits de l’homme ;
- elle devrait mettre l’accent sur les besoins de la personne qui découlent d’obstacles dans la société plutôt que des besoins liés au handicap ;
- elle devrait prendre en compte le souhait et les préférences de la personne et les respecter ;
- et elle devrait permettre aux personnes handicapées de participer pleinement à la prise de décisions

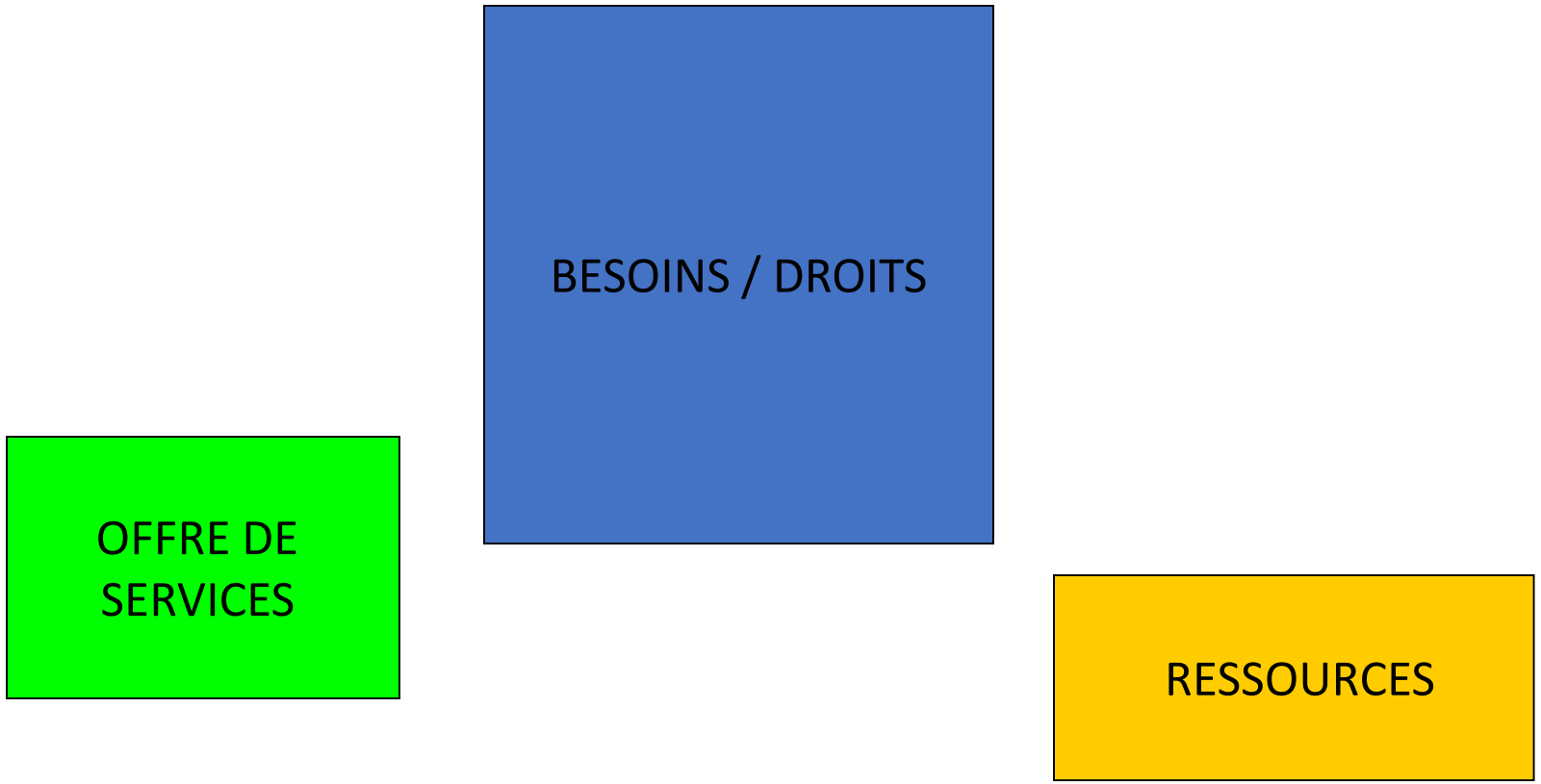
S’éloigner de l’incapacité de travailler

- Il est nécessaire d'étudier plus avant la meilleure façon d'articuler:
  - la justification de la sécurité du revenu / du soutien
  - sans exclure et décourager les individus du monde du travail et
  - sans perdre la légitimité et l'adhésion politique / populaire
- S'appuyant sur l'approche du retour au travail sans ignorer les obstacles et la discrimination sur le marché du travail:
  - Passer de «il/elle ne peut pas travailler» à «il/elle n'est pas en mesure de travailler en raison des obstacles et du manque de soutien dans l'environnement de travail»
  - Accepter le fait que la conditionnalité ne contribue guère à l’intégration de la main-d’œuvre - Recherche sur la conditionnalité au Royaume-Uni (Dwyer, 2018)

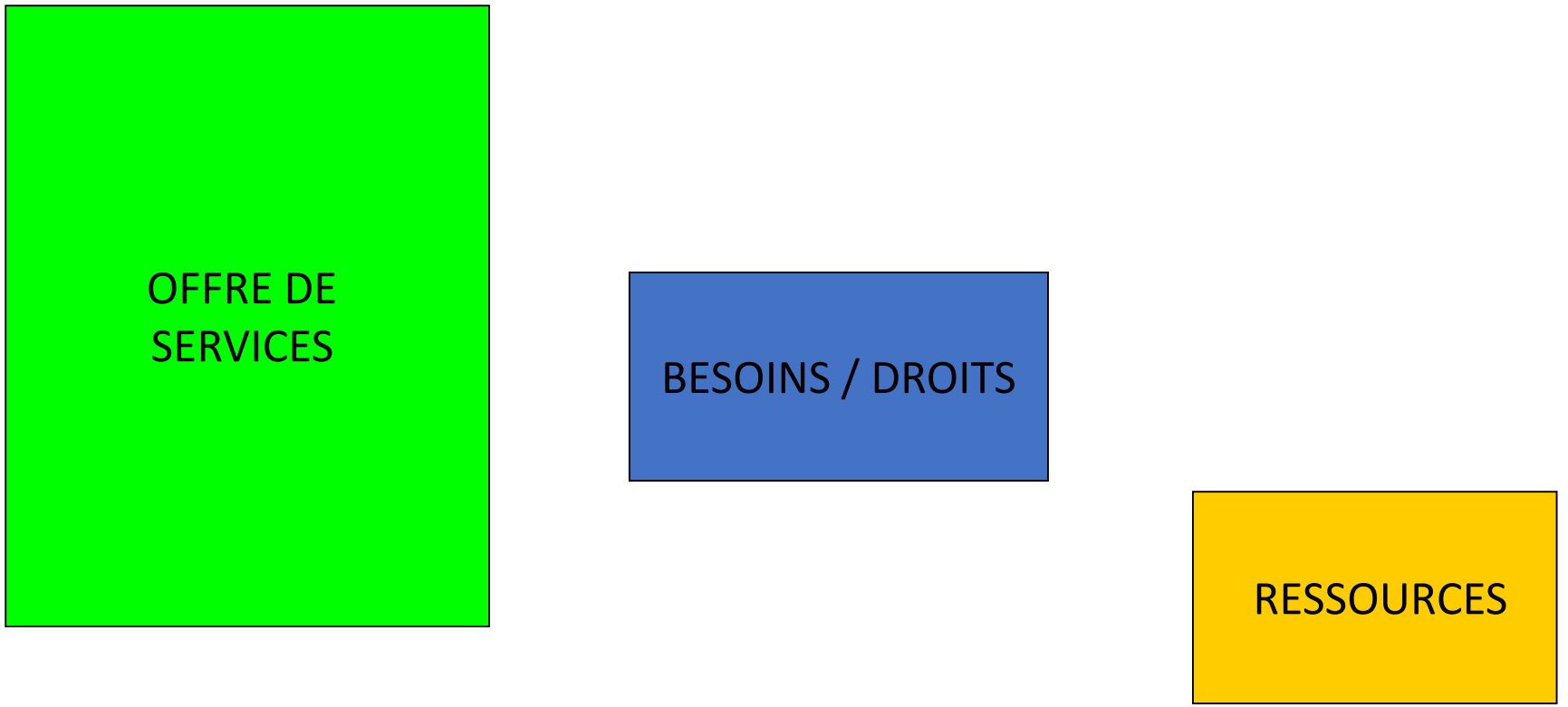
Quels sont les facteurs guidant la réforme de l’évaluation?

Pourquoi une refome?

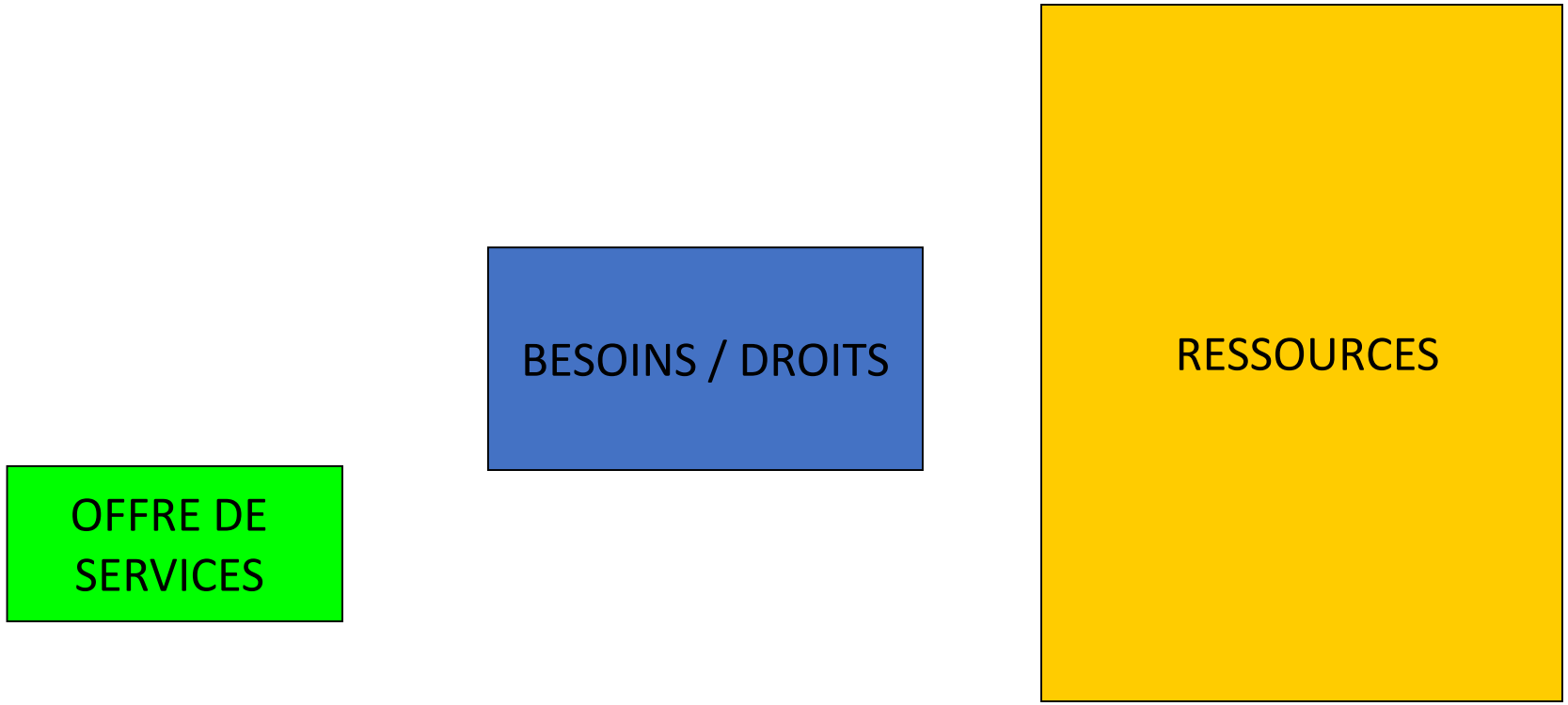
Conformité CDPH/ Besoins et droits? = listes d’attente + création de nouveaux services et augmentations des ressources



Offre de services ? = Listes d’attente mais biaisés car basé sur l’offre et non sur le besoin

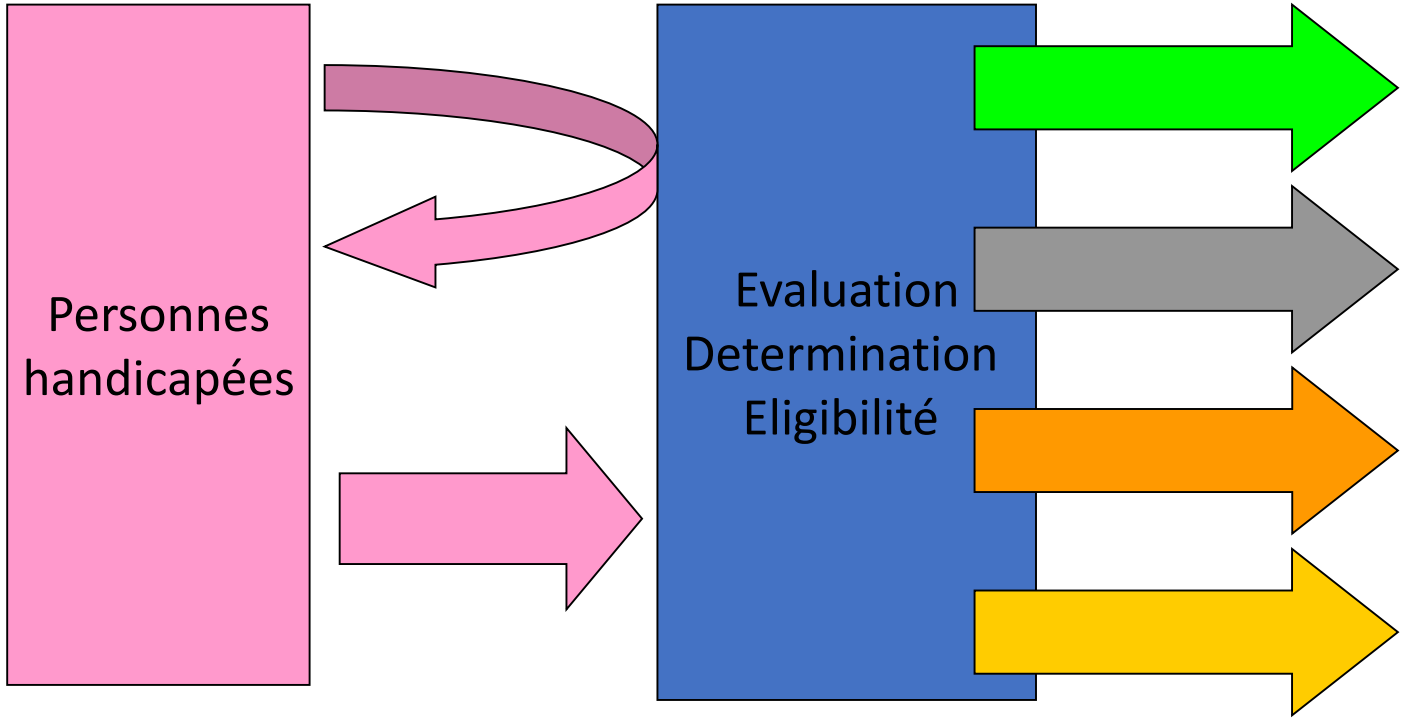


Ressources : le faux equilibre: pas de liste d'attente car on evalue et accorde en fonction des ressources disponibles ou on diminue l'accès

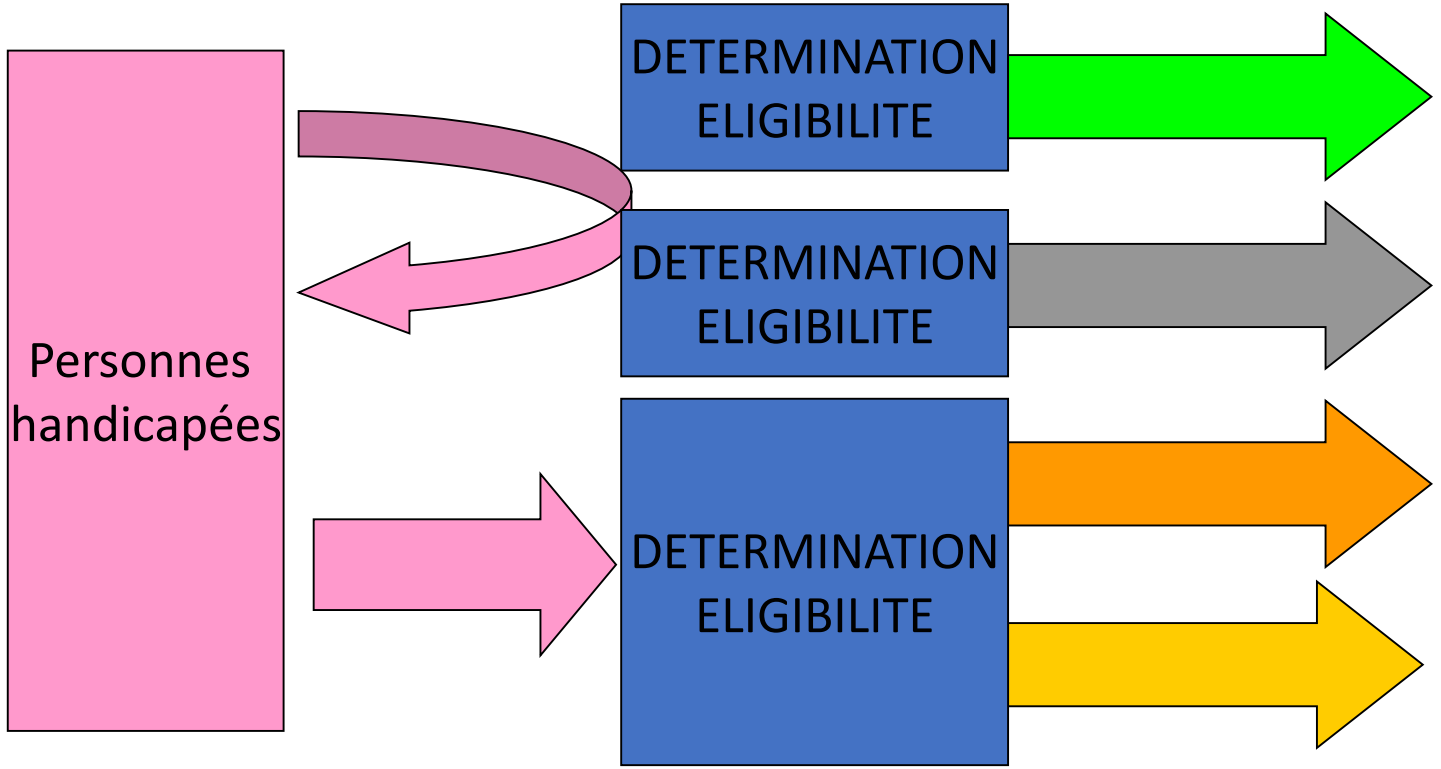


Quels dispositifs?

“Guichet unique”



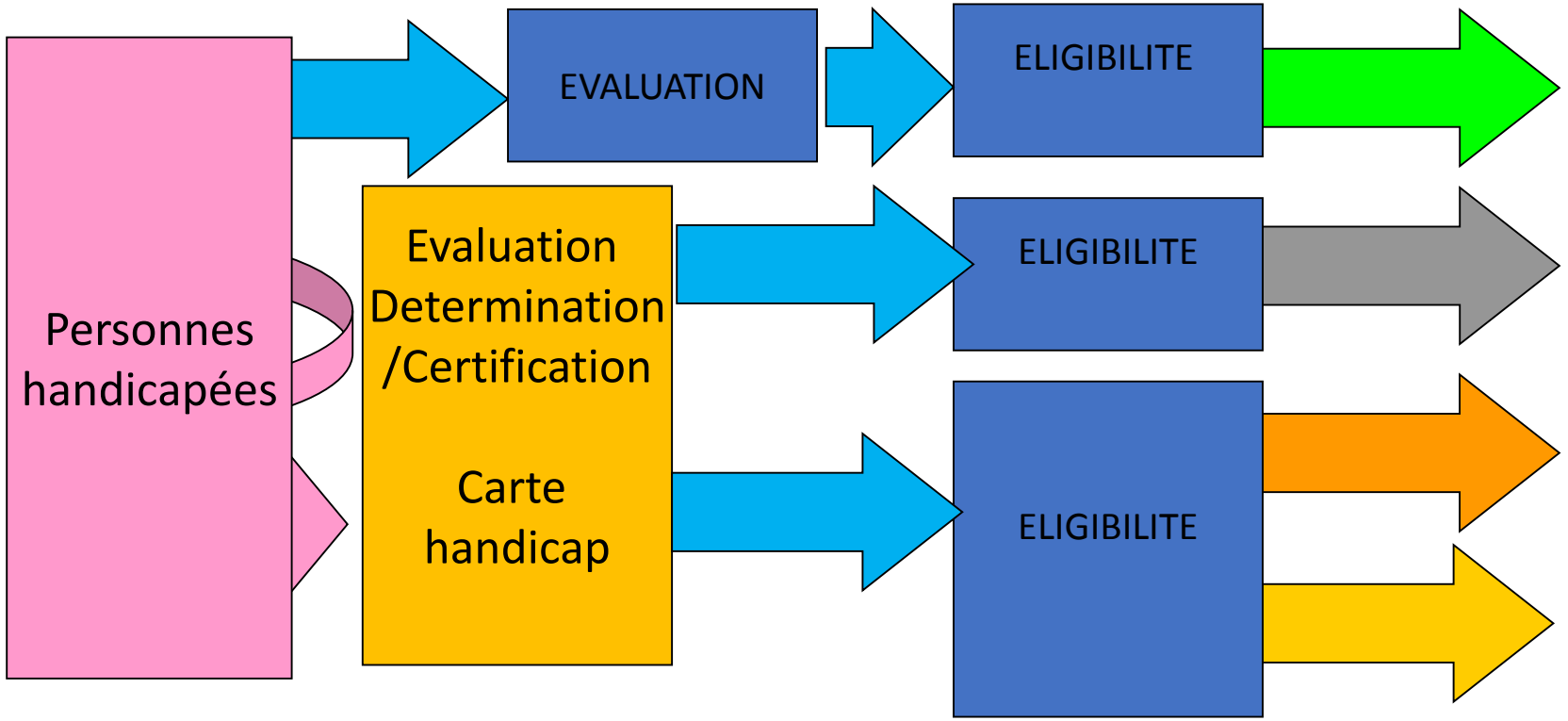
Différents points d'entrée



Pour et contre

	PRO	CONS
Guichet unique	Simplicité et moins d'inconvénience pour les personnes handicapées et leur famille	Si rejet alors possiblité de n'avoir aucun soutien Moins de responsabilisation des autres services/minstères
Différents points d'entrées	Si rejeté dans une procédure, les personnes ont d'autres "chances" avec les autres Responsabilisation des divers ministères et services	Lourd pour pour les personnes handicapées et leur famille Cout associés aux différentes procédures Multiples "definition" et complexité

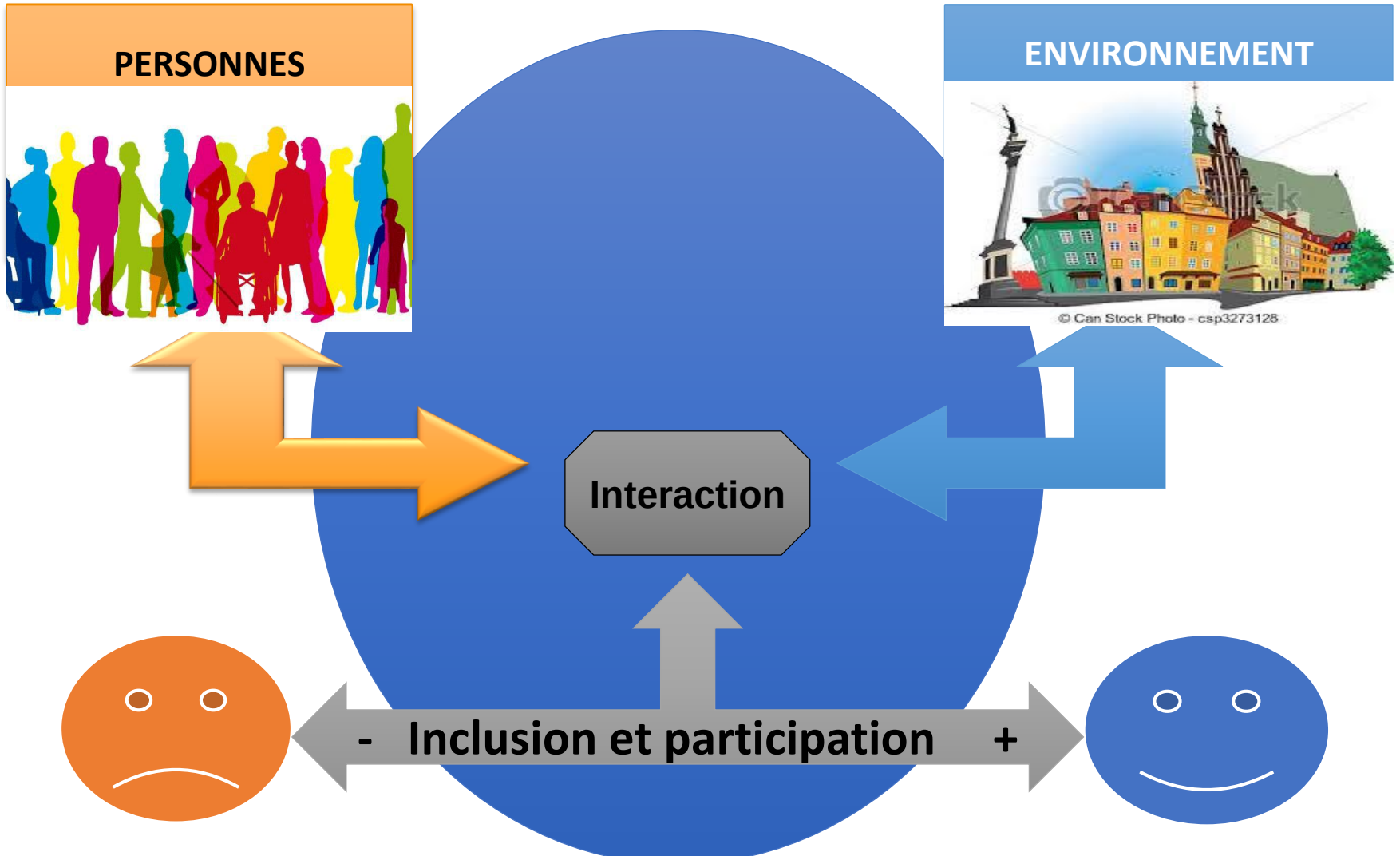
Une approche mixte



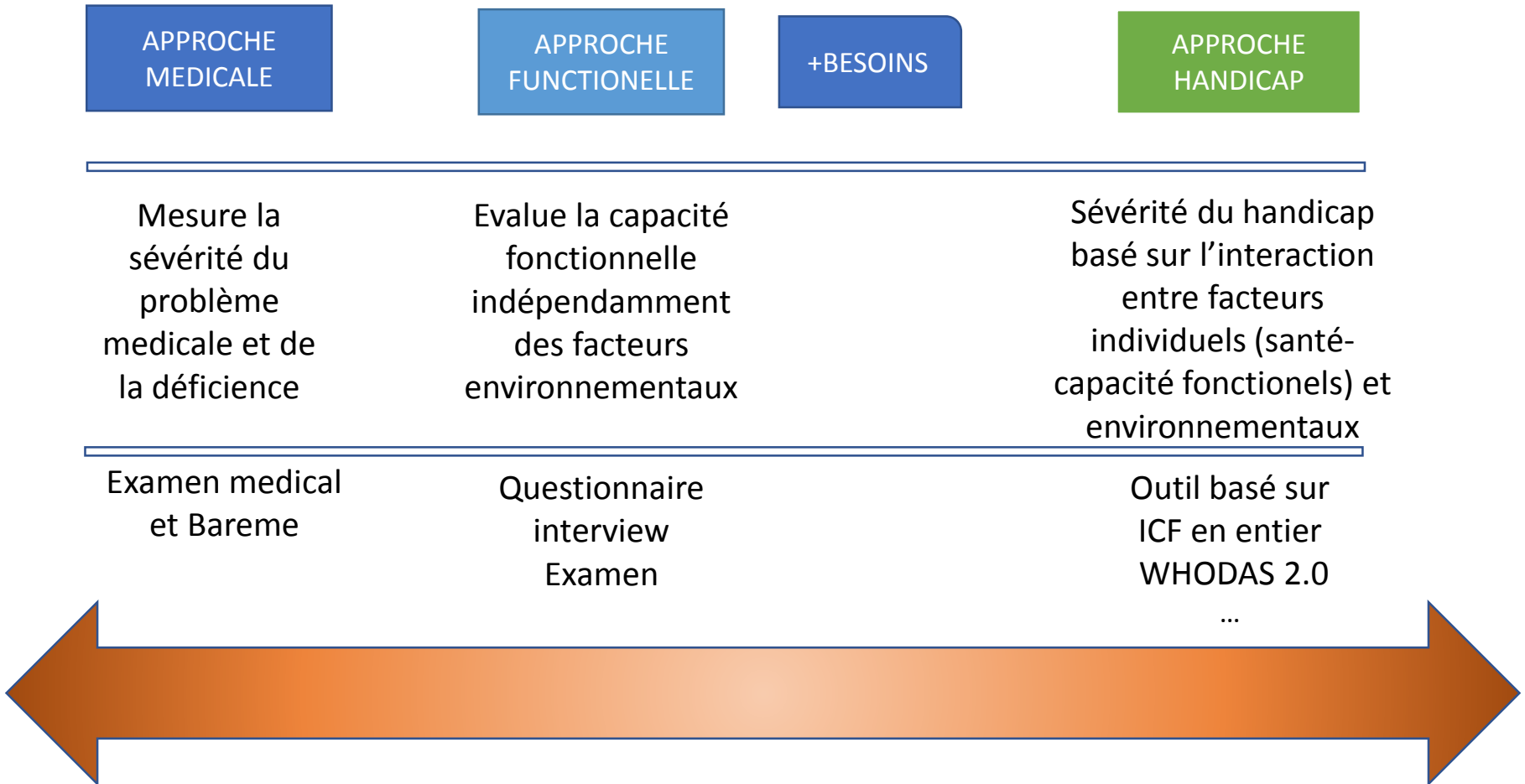
In this approach, there is a main disability certification which become part of the different eligibility determination processes

Quelle evaluation?

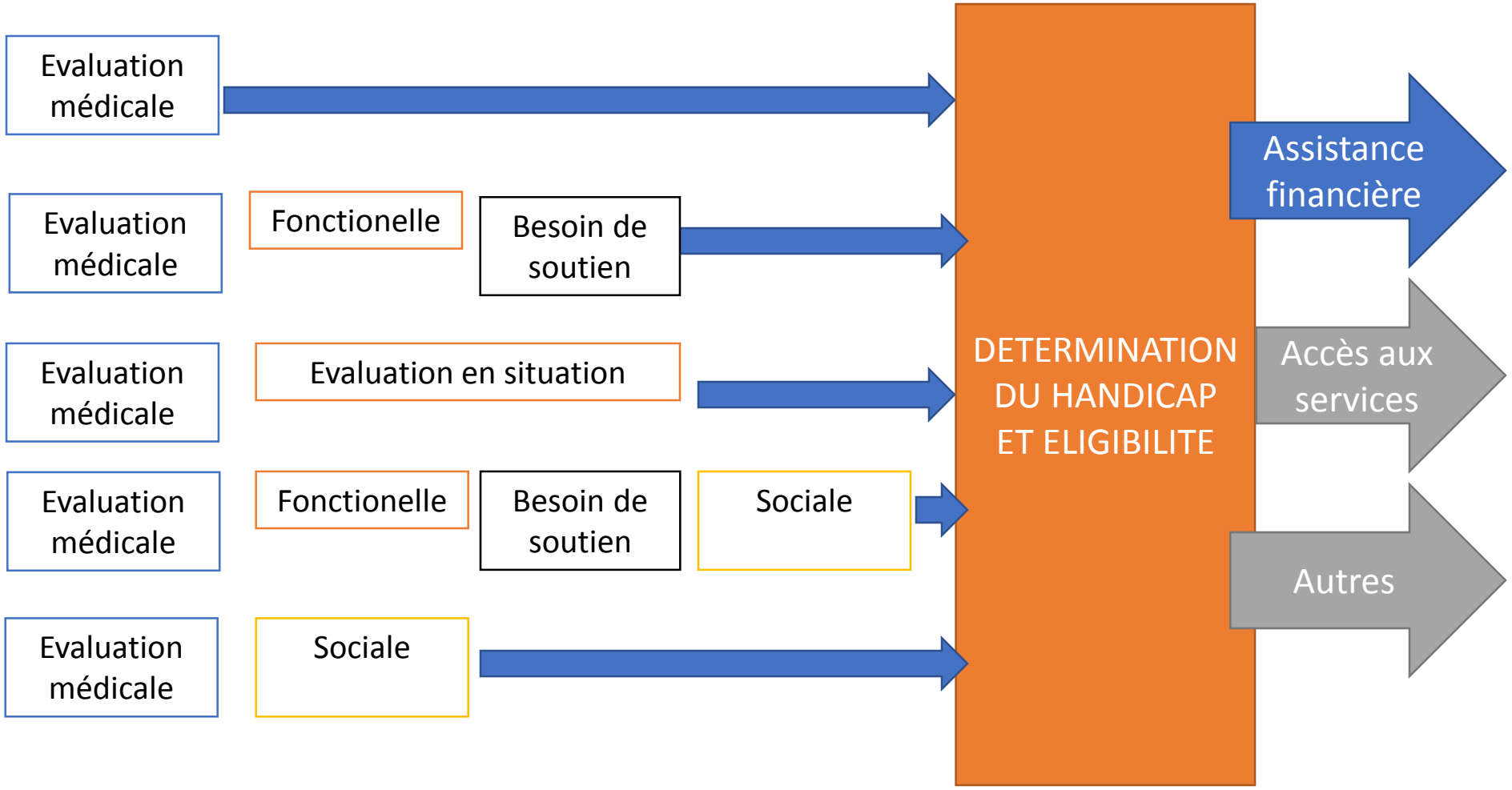
Qu’est ce qui est evalué?



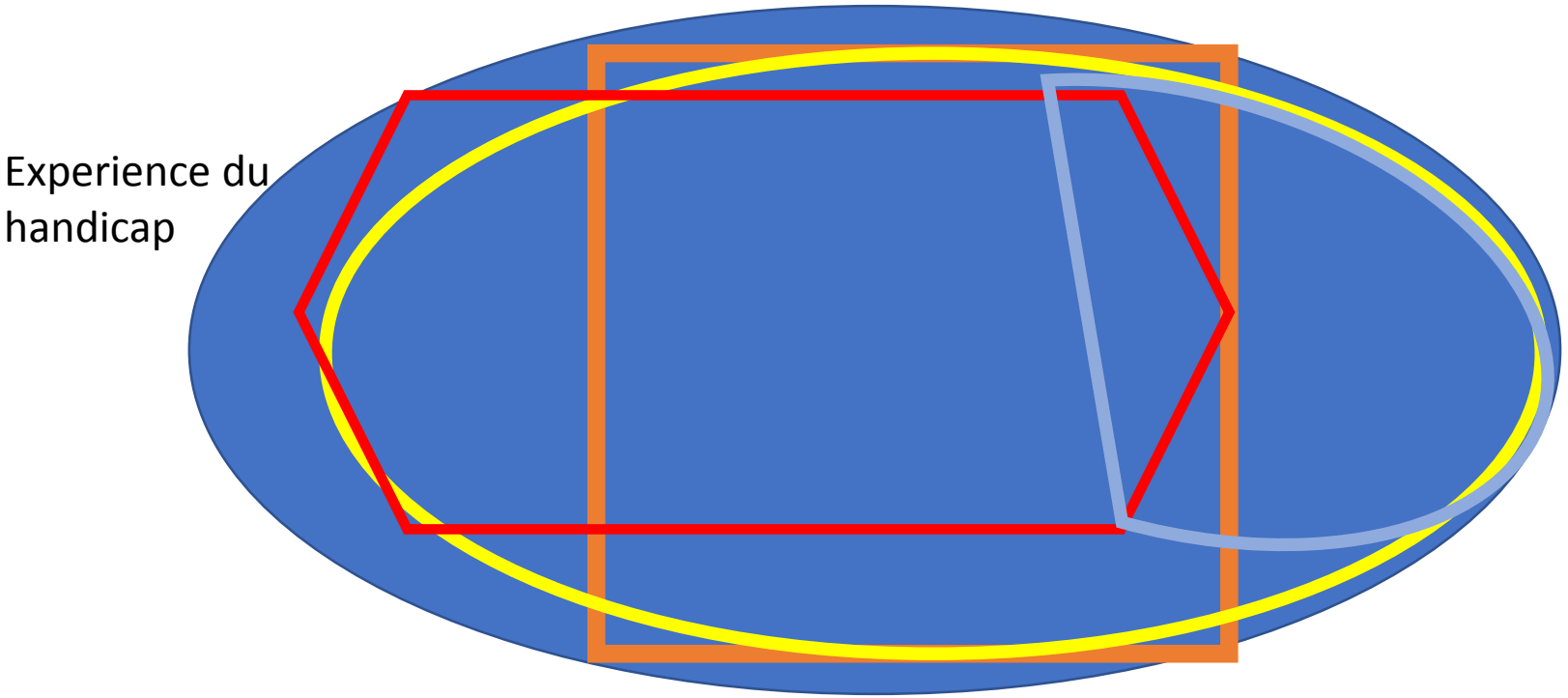
Quels modèles? (Bickenbach, 2015)



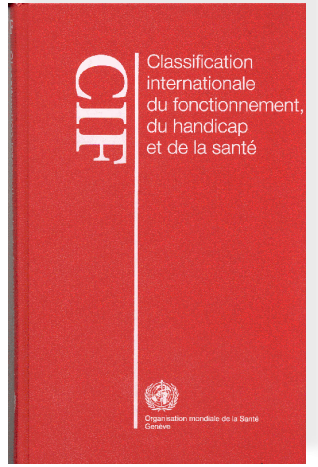
Différent scenarios

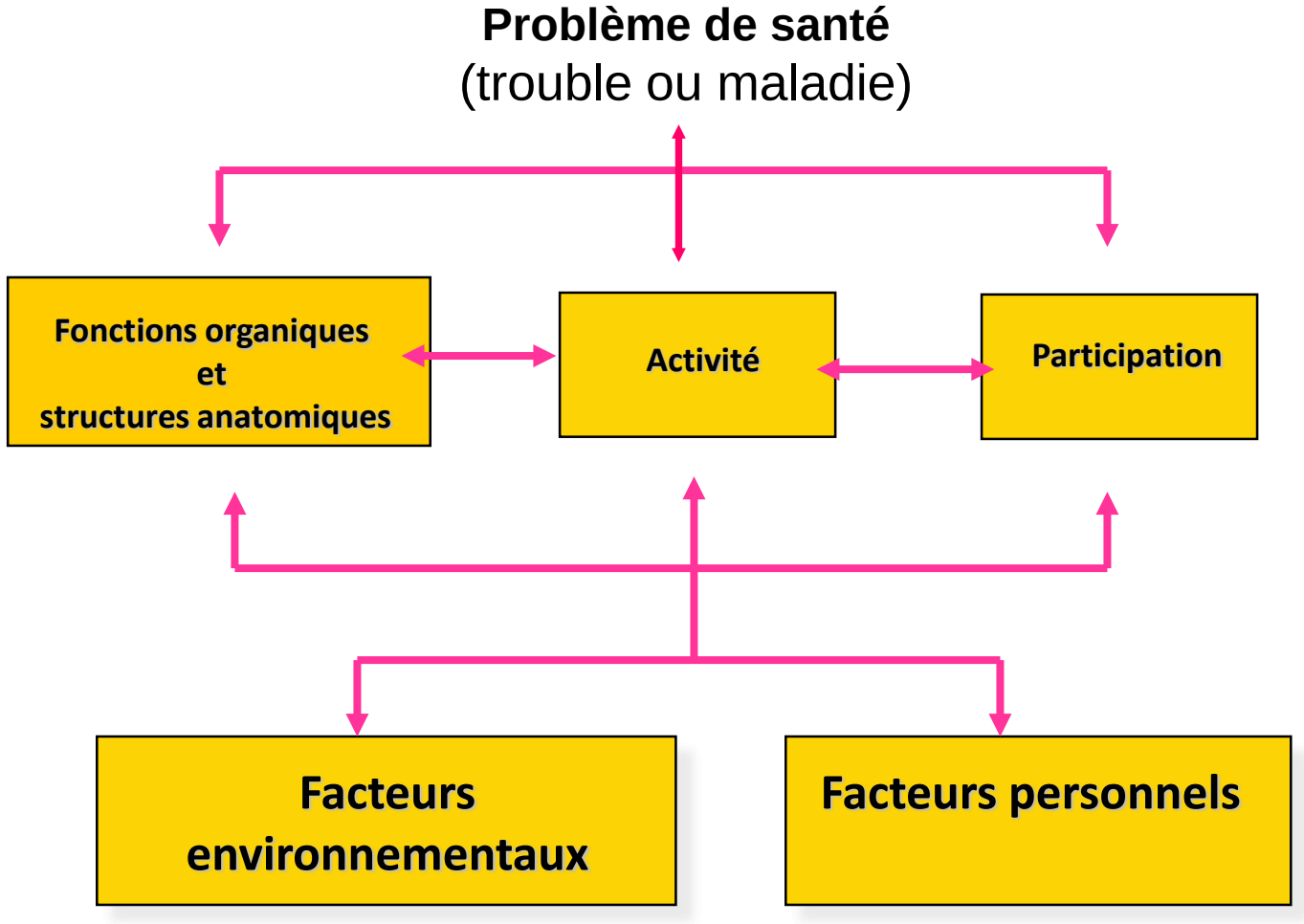


L’évaluation est toujours une représentation partielle de l’expérience du handicap



Classification Internationale du Fonctionnement, du handicap et de la santé : CIF (révision de la CIDIH adoptée par l'OMS en 2001)



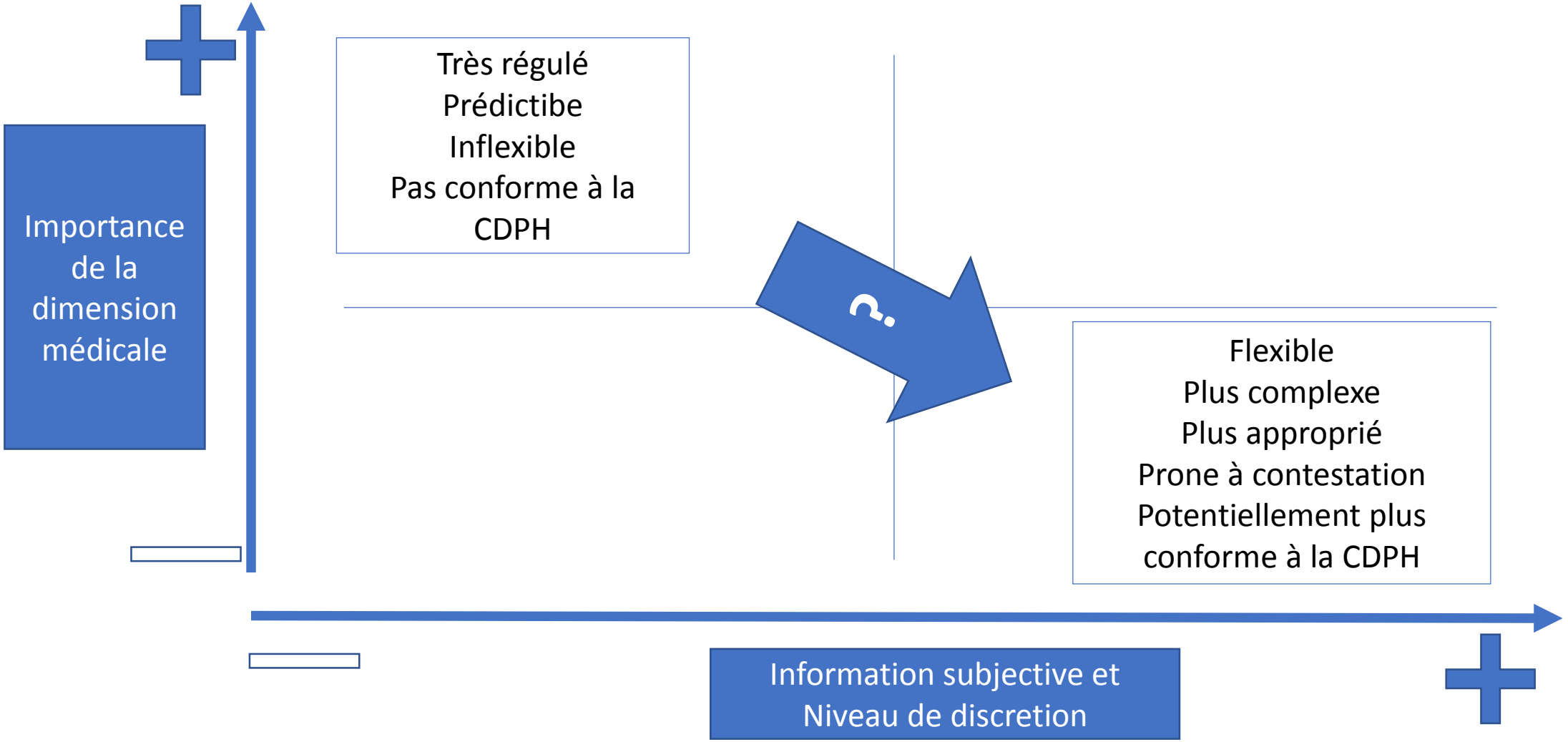


Débats

- Comment “objectiver” l’expérience individuelle du handicap?
- Doit-on necessairement complexifier les outils?
- Comment éviter une disparité et inegalités dans l’accès aux droits?

Qu’est ce qui contribue à la décision?

(based on Kidd, 2017 based on on Bolderson et al (2002)



Sources d’information

- Certificat médical de médecin généraliste ou spécialiste
- Antécédents médicaux
- Questionnaire
- Interview semi-dirigée
- …

Qui fait l’évaluation?

- Medecins
- Équipes multidisciplinaires
- Travailleur social
- ….

Tendances en Europe (voir Rapport ANED à venir)

- De nombreux pays réforment leur évaluation du handicap en raison de differents éléments :
  - austérité
  - conformité à la CDPH
- Tous les pays ont une évaluation médicale jouant un part plus ou moins importante du processus d'évaluation et de détermination de du handicap
- La plupart des pays incluent une évaluation fonctionnelle et, dans certains cas, des besoins de soutien (soins).

Que faire des données recueillies lors de l'evaluation?

- Les données collectées sur l'évaluation du handicap sont-elles utilisées pour la planification et le suivi des politiques?
- Quels sont les besoins de soutien des personnes?
- Qui accède au soutien? Allocation?
- Quel est l'impact de ces mesures?
- Quels sont les défis rencontrés par les enfants, les femmes, les adultes et les personnes âgées?

Enjeux legaux et technique?

- Légal
  - Quelle est la définition juridique du handicap liée à la détermination et à l’évaluation?
  - Est-elle en accord avec la CDPH?
  - Quel cadre juridique régit l'évaluation?
  - Possibilités d'appel?
- Technique:
  - Quelle est la classification utilisée?
  - Qui est le personnel impliqué / nécessaire pour l'évaluation?
  - Quel professionnel et information pèsent le plus dans la décision?
  - Système d'Information
- Accès
  - Le processus est-il simple? Gratuit?

Enjeux politiques?

- Pour les OPH:
  - accéder au support et contrôler le partage des ressources
- Pour les professionnels et les institutions:
  - résistance au changement, à la perte et aux gains…
- Pour le gouvernement
  - Fournir le soutien et contrôler les dépenses
  - Éviter la fraude

Conforme à la CDPH?:

- Une évaluation conforme à la CDPH devrait respecter les principes suivants:
  - Respecter la dignité de la personne
  - Accessibilité totale (informations, réunions, etc.)
  - Ayant été conçu avec la participation d'OPH représentatives
  - Couverture à l'échelle nationale (stratégie de sensibilisation proactive) et attention particulière aux personnes les plus défavorisées (rurales, éloignées, etc.)
  - Respecter la diversité des handicaps
  - Inclure l'évaluation des besoin de soutien et des obstacles
  - Respect de la vie privée (des données)
  - Sensible au genre
  - OPH impliquées
  - Rampe d'accès au support
  - Ne devrait jamais être utilisé pour restreindre la reconnaissance ou l'exercice des droits
  - Devrait avoir une procédure d'appel
  - Devrait être simple pour des raisons de clarté et de transparence

- Faire en sorte que les processus d'évaluation du handicap soient conformes à la CDPH fait partie des obligations des États parties

Merci!

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- OECD database

The impact of the Cross-border Healthcare Directive on access to care for persons with disabilities

Trier, 2 October 2018

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1

GUIDING PRINCIPLES OF DIRECTIVE 2011/24/EU

Directive 2011/24/EU of 9 March 2011 on the application of patients' rights in cross-border healthcare (deadline for transposition: 25 October 2013 - applicable in the EU and EEA).

2

Framework of the Directive

- Under the “freedom to provide services”:
  - health professionals are service providers
  - patients are recipients of services (even if the healthcare is free)
- Consequently, patients are:
  - free to receive healthcare in their State of residence from a healthcare provider established in another Member State
  - entitled to travel to another Member State to receive medical services

3

althcare without prior authorisation

- Prior authorisation by the Member State of affiliation must not be required in order for an insured person to receive healthcare in another Member State
  - Reimbursement of healthcare by the Member State of affiliation as if it had been provided in that country (provided that the costs would be refundable in that State)
  - Reimbursement up to the level of costs that would have been assumed had the same healthcare been provided on its territory

4

althcare without prior authorisation

- Comparison of Healthcare Directive and coordinating regulations
  - Scheduled treatment (medical consultation, purchase of medicinal products, etc.)
    - More favourable system than under Regulation 883/2004
      - 883/2004 requires prior authorisation
      - the upfront payment of costs required by the Directive is not an obstacle to treatment
      - Directive offers the possibility of accessing treatment outside the social security system ("non-contracted providers")
  - Unplanned treatment (treatment that becomes medically necessary during a stay)
    - Less favourable system than under Regulation 883/2004
      - 883/2004: provision via the EHIC under the conditions existing in the State of stay with potential waiver of costs, even if the treatment is not in the range of healthcare offered in the State of affiliation!
      - The directive offers preferable terms if the State of affiliation offers more generous provision (but upfront costs)

5

lealthcare with prior authorisation

- Some healthcare may be subject to prior authorisation
  - Healthcare which is subject to planning requirements relating to the aim of ensuring sufficient and permanent access to a balanced range of high-quality treatment or to the wish to control costs and avoid, as far as possible, any waste of financial, technical and human resources.
    - Condition 1: overnight hospital accommodation for at least one night
    - Condition 2: use of highly specialised and cost-intensive medical infrastructure or medical equipment;

    Member States shall notify the categories of healthcare in question to the Commission.

6

lealthcare with prior authorisation

- The Member State of affiliation may not refuse to grant prior authorisation
  - when the patient is entitled to the healthcare in question
  - and when this healthcare cannot be provided on its territory within a time limit which is medically justifiable, based on an objective medical assessment of the patient's medical condition, the history and probable course of the patient's illness, the degree of the patient's pain and/or the **nature of the patient's disability** at the time when the request for authorisation was made or renewed

<u>The Member State of affiliation shall publish a list of the healthcare that is subject to prior authorisation</u>

7

Healthcare with prior authorisation

- The Healthcare Directive is of secondary interest compared with Regulation 883/2004
  - Assumption of costs: upfront payment by the patient (Directive) *versus* reimbursement between social security institutions (Regulation)
  - However the Directive is still useful
    - Complementary "Vanbraekel Reimbursement": if the assumption of costs by the State in which treatment is given (Regulation) is less favourable than in the State of affiliation (Directive), there is a right to complementary reimbursement by the latter.
    - If the State of affiliation refuses to give prior authorisation on the basis of Regulation 883/2004

8

Recognition of prescriptions

- Member States shall ensure that medicinal products prescribed in another Member State for an individual named patient may be dispensed on their territory.
- Any restriction on the recognition of a given prescription is prohibited
  - The recognition of such prescriptions shall not affect national rules governing prescribing and dispensing [...] including generic substitution.

9

Administrative procedures

- Member States shall set out **reasonable periods of time** within which requests for cross-border healthcare must be dealt with and make them public in advance.
- When considering a request for cross-border healthcare, Member States shall take into account:
  - a) the specific medical condition;
  - b) the urgency and individual circumstances.

10

Administrative procedures

NHS England

FUNDING FOR TREATMENT IN THE EUROPEAN ECONOMIC AREA (EEA) APPLICATION FORM

Part 1: Application Route	
Treatment	**On what basis is the treatment being provided?** ☐ **Private system** or ☐ **State system**
Application route **(please tick)**	☐ **S2:** I want to apply for funding via the **S2** route *(apply before treatment and treatment must be in the state system)* ☐ **Directive:** I want to apply for funding via the directive route for a treatment not classed as 'specialised' *(application can be before or after treatment)* ☐ **Directive:** I want to apply for funding for a *specialised* treatment subject to prior authorisation *(apply before treatment only)* ☐ **Unsure** of funding route

Medical Delay	**Are you seeking treatment abroad because of a medical delay in being treated by the NHS?** ☐ **Yes** ☐ **No**
	If Yes, please provide evidence that this delay was deemed to be "medically unacceptable" and assessed as such by a UK NHS clinician.

11

National contact points (NCPs)

- The national contact point gives patients information on which healthcare providers are subject to these standards and guidelines, and information on the accessibility of hospitals for persons with disabilities.
  - NCPs shall facilitate the exchange of information enabling patients to make use of their rights to cross-border healthcare

12

Reimbursement of related costs

- **Transport costs**
  - Reimbursed in accordance with national legislation in the State of affiliation (CJEC 15 June 2006, C-466/04, Acerada Herrera)

- The Member State of affiliation may decide to **reimburse other related costs**, such as accommodation and travel costs, or extra costs which persons with disabilities might incur due to one or more disabilities when receiving cross-border healthcare, in accordance with national legislation and on the condition that there is sufficient documentation setting out these costs.

13

Medical follow-up

- Facilities benefitting persons with disabilities
  - Where a patient has received cross-border healthcare and where medical follow-up proves necessary, the same **medical follow-up** is available as would have been if that healthcare had been provided on its territory
  - Patients who seek to receive or do receive cross-border healthcare shall have remote access to or have at least a copy of their **medical records**

14

European reference networks

- The Commission shall support Member States in the development of **European reference networks (ERN)** between healthcare providers and centres of expertise in the Member States, in particular in the area of **rare diseases**
  - to help realise the potential of European cooperation regarding highly specialised healthcare
  - to facilitate improvements in diagnosis and the delivery of high-quality, accessible and cost-effective healthcare for all patients with a medical condition requiring a particular concentration of expertise
  - to help Member States with an insufficient number of patients with a particular medical condition or lacking technology or expertise to provide highly specialised services of high quality

15

Rare diseases

- The Commission shall support Member States in cooperating in the development of diagnosis and treatment capacity, by aiming to:
  - make health professionals aware of the tools available to them at Union level to assist them in the correct diagnosis of rare diseases
  - make patients, health professionals and those bodies responsible for the funding of healthcare aware of the possibilities offered by Regulation (EC) No 883/2004 for referral of patients with rare diseases to other Member States even for diagnosis and treatments which are not available in the Member State of affiliation.

16

DIRECTIVE 2011/24/EU IN PRACTICE

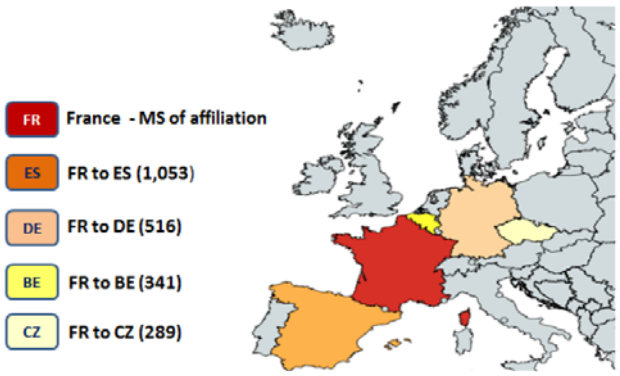
Crossborder healthcare stats

3.4 Patient Mobility with Prior Authorisation – time taken & reimbursement made

Country of affiliation	Maximum time for processing (Y/N)	Maximum time	Average Processing time (days)	aggregated amount reimbursed	in Euro
Austria	Y	5	3	no data	no data
Belgium	Y	45	No data	14,962.75	14,962.75
Bulgaria	Y	63	255	4,032.00	2,062.00
Croatia	Y	60	30	3,000.00	396.00
Cyprus	Y	60	35	21,513.44	62,712.00
Czech Republic	N/A	N/A	N/A	N/A	N/A
Denmark	Y	10	19.4	446,735.25	59.983.17
Estonia	N/A	N/A	N/A	N/A	N/A
Finland	y	14	No data	no data	no data
France	no data	no data	No data	21,750,698.70	21,750,698.70
Germany	no data	no data	No data	no data	no data
Greece	N/A	N/A	60	no data	no data
Hungary	no data	no data	No data	no data	no data
Ireland	y	30	24.9	1,752,132.01	1,752,132.01
Italy	Y	30	11.2	383,369.64	383,369.64
Latvia	Y	30	No data	no data	no data
Lithuania	N/A	N/A	N/A	N/A	N/A
Luxembourg	N	N/A	40	no data	no data
Malta	N	N/A	4	4,951.47	4,951.47
Netherlands	N	N/A	N/A	N/A	N/A
Poland	y	30	No data	0.00	0.00
Portugal	Y	35	No data	no data	no data
Romania	Y	5	3	no data	no data
Slovakia	Y	15	56	375,549.96	375,549.96
Slovenia	Y	60	34	796.23	796.23
Spain	Y	45	17	37,859.32	37,859.32
Sweden	no data	no data	No data	no data	no data
UK	Y	20	11,375	240,401.00	269,439.00
Norway	N/A	N/A	N/A	N/A	N/A
Iceland	no data	no data	No data	no data	no data
TOTAL					24,654,929.08

Crossborder healthcare stats

Figure 5 Mobility from France with Prior Authorisation



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Crossborder healthcare stats

Table 3.2 Requests for Prior Authorisation – Accepted

Country of affiliation	Authorised requests - overnight stay Reason 1	Authorised requests - specialised care reason 2	Authorised requests - high risk care reasons 3-5
Austria	0	0	0
Belgium	19	11	0
Bulgaria	5	0	0
Croatia	0	1	0
Cyprus	13	0	0
Czech Republic	N/A	N/A	N/A
Denmark	10	11	0
Estonia	N/A	N/A	N/A
Finland	N/A	N/A	N/A
France	no data	no data	no data
Germany	no data	no data	no data
Greece	3	0	0
Hungary	0	0	0
Ireland	197	0	0
Italy	66	19	9
Latvia	0	0	0
Lithuania	N/A	N/a	N/A
Luxembourg	no data	no data	no data
Malta	2	0	0
Netherlands	N/A	N/A	N/A
Poland	1	0	0
Portugal	1	1	0
Romania	0	0	0
Slovakia	156	42	0
Slovenia	0	2	0
Spain	4	3	0
Sweden	no data	no data	no data
UK	108	12	0
Norway	N/A	N/A	N/A
Iceland	0	0	0
totals	585	102	9

20

European reference networks

- 24 ERN https://ec.europa.eu/health/ern/networks_en
- Example: **European reference network** on bone disorders (BOND)

  ”The network will develop guidelines, leading to the development and dissemination of best practice. As new therapeutics are developed, the network will work to ensure rapid access to studies for affected patients. BOND will enable skill development through eHealth and telemedicine platforms, alongside working visits, training courses and dissemination activities. The network aims to reduce time to diagnosis with fewer inappropriate tests, more accurate diagnosis and new viable treatments to be available within 2 to 3 years”.

21

National contact points (NCPs)

- Almost five years after the implementation of the Directive, patients’ awareness of their rights, of the possibilities of accessing health services abroad and of the existence of NCPs is still low
- Information on patient’s rights, quality and safety standards, and reimbursement of cross-border healthcare costs require additional consideration and improvement
- Information provision for incoming patients is in general less complete than that for outgoing patients

Source: **Final report - Study on cross-border health services: enhancing information provision to patients**

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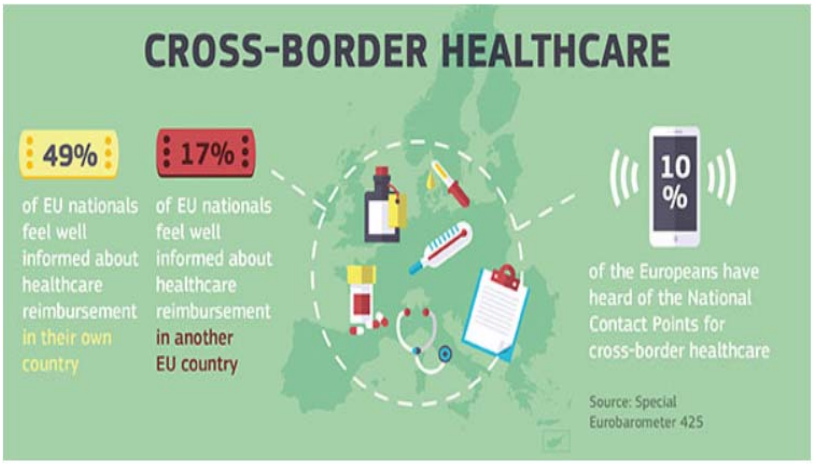
Accessibility of information



Conclusion

- "Patient mobility for planned healthcare — under both the Directive and the Social Security Regulations — remains low, whilst patient mobility in terms of unplanned healthcare seems to be considerably higher. France, Luxembourg, and possibly Finland and Denmark appear to be exceptions to this general observation. The level of use of planned healthcare elsewhere is far below the potential levels suggested by the number of people indicating in the Eurobarometer survey that they would consider using cross-border healthcare"
  - number of Member States were late implementing the Directive
  - number of citizens who are aware of their general rights to reimbursement is extremely low
  - A considerable number of Member States where the obstacles placed in the way of patients by health systems are significant, and which, in some cases at least, appear to be the result of intentional political choices
  - unwillingness of patients to travel; language barriers; price differentials between Member States; acceptable waiting times for treatment in the Member State of affiliation
  - demand may be catered for under local bilateral arrangements

This training session is funded under the 'Rights, Equality and Citizenship Programme 2014-2020' of the European Commission.

COORDINATION OF SOCIAL SECURITY SYSTEMS

Regulations (EC) 883/2004 of 29 April 2004 and 987/2009 coordinating social security systems.

25

Benefits for persons reliant on care

- Benefits for persons reliant on care are essentially intended to supplement sickness insurance benefits to which they are, moreover, linked at the organisational level, in order to improve the state of health and the quality of life of persons reliant on care.
- In those circumstances, even if they have their own characteristics, such benefits must be regarded as **sickness benefits** within the meaning of Regulation No 1408/71(883/2004).
- Sickness benefits in cash or in kind?
  - **In cash** ("financial aid which enables the standard of living of persons requiring care to be improved as a whole, so as to compensate for the additional expense brought about by their condition"): can be exported from the insuring State (prohibition of residence conditions)
  - **In kind (**"benefits consisting in the direct payment or reimbursement of expenses incurred in specialised centres as a result of the insured person's reliance on care"): payment, ultimately by the State of affiliation, for services in the place of residence or stay as if the beneficiary were affiliated there.

Directive 2011/24 does not apply to long-term care!!

26

Benefits for persons reliant on care

- Insurance giving entitlement to full or partial direct payment of certain expenditure entailed by the insured person's reliance on care such as **care provided in the home, in specialised centres or hospitals, the purchase of equipment required by insured persons, the carrying out of work in the home** and the payment of **monthly financial aid allowing the insured to choose the method of assistance** they prefer and, for example, to remunerate in one form or another the third party assisting them, is a **sickness benefit in kind** within the meaning of Regulation No 1408/71(883/2004).
  - This benefit must be paid by the country concerned (Germany) to persons with social insurance in that country, even if they are resident in France (CJEC 5 March 1998, aff.C-160/96, Molenaar)
  - The condition of residence in Germany to receive care is incompatible with the regulation.
  - Social contributions must be paid in Germany

27

Benefits for persons reliant on care

- A care allowance (*Pflegegeld*) in the form of a **flat-rate contribution** to provide a benefit assisting persons reliant on care in order to improve their chances of living an independent life in accordance with their needs is a cash sickness benefit within the meaning of Regulation 1408/71 (883/2004)
  - The beneficiary of an Austrian retirement pension living in Germany may receive Austrian *Pflegegeld* (CJEC 8 March 2001, C-215/99, Jauch)

28

Benefits for persons reliant on care

- A benefit for persons reliant on care consisting of the **payment of a sum of money to reimburse costs** is an in-kind sickness benefit.
  - The insured person therefore receives the payment, in the State of residence, of equivalent benefits in kind (paid by the State of affiliation), but not the export of the benefit from the State of affiliation (CJEC 12 July 2012, C-562/10, Commission v/ Germany - complaint introduced against the German authorities in respect of reimbursement of care services and the costs relating to the hire of care equipment by a German couple who stayed in Spain for two months).
  - …What if such a benefit in kind does not exist in the State of residence? European Union law [art. 21 TFEU + freedom to provide services] is powerless to compel the insuring State to pay its benefits outside its territory = the coordinating regulations do not make it possible to guarantee movement without loss of benefits (CJEC 16 July 2009, aff.C-208/07, Von Chamier)

29

Benefits for persons reliant on care

- **Personal assistance which entails covering the costs to which a severely disabled person's everyday activities give rise**, with the aim of enabling that person, who is not economically active, to study in higher education, therefore does not fall within the concept of 'sickness benefit'.
  - Refusing to pay this disputed benefit to a Finnish beneficiary on the grounds that he is studying in Estonia is a restriction of the freedom of movement and residence in the territory of Member States as recognised in TFEU by article 21 (1) (CJEU 25 July 2018, C-679/16, A.)
    - A disabled person exercising freedom of movement may therefore be better protected when the care allowance is excluded from the coordinating regulations than when it is covered! (see Von Chamier)

30

Impact de la directive « soins de santé transfrontaliers » sur l'accès aux soins des personnes handicapées

Trier, 2 octobre 2018

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1

PRINCIPES DIRECTEURS DE LA DIRECTIVE 2011/24/UE

Directive 2011/24/UE du 9 mars 2011 relative à l'application des droits des patients en matière de soins de santé transfrontaliers (date limite de transposition : 25 octobre 2013 – applicable dans l'UE et l'EEE)

2

Cadre de la directive

- Sous l'angle « libre prestation des services »:
  - le professionnel de santé est un prestataire de services
  - le patient est un destinataire de services (même si les soins sont gratuits)
- Conséquences : le patient est:
  - libre de recevoir dans son État de résidence des soins dispensés par un prestataire installé dans un autre État membre
  - de se déplacer dans un autre État membre pour qu'une prestation médicale lui soit prodiguée

3

Soins sans autorisation préalable

- Est interdite la condition d'autorisation préalable par l'Etat d'affiliation pour qu'un assuré social bénéficie de soins de santé dans un autre État membre
  - Remboursement des soins par l'Etat d'affiliation comme s'ils avaient été prodigués dans ce pays (sous réserve qu'ils y soient remboursables)
  - Remboursement à hauteur des coûts qu'il aurait pris en charge si ces soins avaient été dispensés sur son territoire

4

Soins sans autorisation préalable

- Comparaison directive « soins de santé »/ règlements de coordination
  - Soins programmés (consultation médicale, achat de médicaments…)
    - système plus favorable que celui du règlement 883/2004
      - 883/2004 repose sur une demande d'autorisation préalable
      - l'avance des frais requis par la directive n'est pas un frein aux soins
      - Possibilité avec la directive d'accéder aux soins hors « système sécurité sociale » (« non-contracted providers »)
  - Soins inopinés (soins qui s'avèrent nécessaires d'un point de vue médical au cours du séjour)
    - Système moins favorable que le règlement 883/2004
      - 883/2004 : prise en charge via la CEAM (EHIC) aux conditions de l'Etat de séjour avec éventuellement dispense de frais, même si les soins ne sont pas dans le panier de soins de l'Etat d'affiliation !
      - Voie de la directive préférable si la prise en charge par l'Etat d'affiliation est plus généreuse (mais avance de frais)

5

Soins avec autorisation préalable

- Certains soins de santé sont susceptibles d'être subordonnés à autorisation préalable
  - Soins soumis à des impératifs de planification liés à l'objectif de garantir sur le territoire de l'État membre concerné un accès suffisant et permanent à une gamme équilibrée de soins de qualité élevée ou à la volonté d'assurer une maîtrise des coûts et d'éviter autant que possible tout gaspillage de ressources financières, techniques et humaines
    - Condition n°1 : séjour hospitalier d'au moins une nuit
    - Condition n°2 : recours à des infrastructures ou à des équipements médicaux hautement spécialisés et coûteux

Les États membres communiquent à la Commission les catégories de soins de santé visées

6

Soins avec autorisation préalable

- L'État membre d'affiliation ne peut refuser d'accorder une autorisation préalable
  - si le patient a droit aux soins de santé concernés
  - si ces soins de santé ne peuvent être dispensés sur son territoire dans un délai acceptable sur le plan médical, sur la base d'une évaluation médicale objective de l'état pathologique du patient, de ses antécédents, de l'évolution probable de sa maladie, du degré de sa douleur et/ou de la **nature de son handicap** au moment du dépôt ou du renouvellement de la demande d'autorisation

L'État membre d'affiliation rend publique la liste des soins de santé soumis à autorisation préalable

7

Soins avec autorisation préalable

- La directive « soins de santé » présente un intérêt secondaire par rapport au règlement 883/2004
  - Prise en charge : avance des frais par le patient (directive) *versus* remboursement entre institutions de sécurité sociale (règlement)
  - Cependant la directive conserve une utilité
    - « complément Vanbraekel » : si la prise en charge par l'Etat de soins (règlement) est moins favorable que celle de l'Etat d'affiliation (directive), droit à un complément de prise en charge par ce dernier
    - Si l'Etat d'affiliation refuse de délivrer l'autorisation préalable sur la base du règlement 883/2004

8

Reconnaissance des prescriptions

- Les États membres veillent à ce que les prescriptions établies pour ce médicament dans un autre État membre pour un patient nommément désigné puissent être délivrées sur leur territoire
- Toute restriction à la reconnaissance d'une prescription donnée est interdite
  - La reconnaissance des prescriptions n'affecte pas les dispositions nationales concernant la prescription et la délivrance (…) y compris la substitution par des génériques

9

Procédures administratives

- Les États membres fixent des **délais raisonnables** dans lesquels les demandes de soins de santé transfrontaliers doivent être traitées et les rendent publics préalablement à leur application.
- Pour l'examen des demandes de soins de santé transfrontaliers, les États membres tiennent compte:
  - a) de l'état pathologique spécifique;
  - b) de l'urgence et des circonstances particulières.

10

Procédures administratives

NHS England

FUNDING FOR TREATMENT IN THE EUROPEAN ECONOMIC AREA (EEA)
APPLICATION FORM

Part 1: Application Route	
Treatment	**On what basis is the treatment being provided?** ☐ **Private system** or ☐ **State system**
Application route **(please tick)**	☐ **S2:** I want to apply for funding via the **S2** route *(apply before treatment and treatment must be in the state system)* ☐ **Directive:** I want to apply for funding via the directive route for a treatment not classed as 'specialised' *(application can be before or after treatment)* ☐ **Directive:** I want to apply for funding for a *specialised* treatment subject to prior authorisation *(apply before treatment only)* ☐ **Unsure** of funding route

Medical Delay	**Are you seeking treatment abroad because of a medical delay in being treated by the NHS?** ☐ **Yes** ☐ **No**
	If Yes, please provide evidence that this delay was deemed to be "medically unacceptable" and assessed as such by a UK NHS clinician.

11

Point de contact national (PCN)

- Les patients reçoivent du **PCN** des informations indiquant quels prestataires de soins de santé sont soumis à ces normes et orientations et des informations sur l'accessibilité des centres hospitaliers aux personnes handicapées
  - Les PCN facilitent l'échange des informations permettent aux patients d'exercer leurs droits en matière de soins de santé transfrontaliers

12

Remboursement de frais connexes

- **Frais de transport**
  - Prise en charge selon les règles de l'Etat d'affiliation (CJCE 15 juin 2006, C-466/04, Acerada Herrera)

- L'État membre d'affiliation peut décider de **rembourser d'autres frais connexes**, tels que les frais d'hébergement et de déplacement, ou les frais supplémentaires que les personnes handicapées peuvent être amenées à exposer, en raison d'un ou de plusieurs handicaps, lorsqu'elles bénéficient de soins de santé transfrontaliers, conformément à la législation nationale et sous réserve de la présentation de documents suffisants précisant ces frais.

13

Suivi médical

- Facilités dont bénéficient les handicapés
  - lorsqu'un patient a bénéficié de soins de santé transfrontaliers et qu'un suivi médical s'avère nécessaire, il doit avoir accès au même **suivi médical** que celui dont il aurait bénéficié si les soins avaient été dispensés sur son territoire
  - les patients qui cherchent à bénéficier ou bénéficient de soins de santé transfrontaliers doivent avoir accès à distance à leur **dossier médical** ou disposent au moins d'une copie de celui-ci

14

Réseaux européens de référence

- La Commission aide les États membres à créer des **réseaux européens de référence (RER)** entre prestataires de soins de santé et centres d'expertise dans les États membres, en particulier dans le domaine des **maladies rares**
  - contribuer à la pleine exploitation des possibilités de coopération européenne dans le domaine des soins de santé hautement spécialisés
  - aider à améliorer le diagnostic et la prestation de soins de santé d'une qualité élevée, accessibles et d'un bon rapport coût-efficacité pour tous les patients dont l'état pathologique nécessite une concentration particulière d'expertise
  - aider les États membres dont le nombre de patients dans un état pathologique particulier est insuffisant, ou qui ne disposent pas de la technologie ou de l'expertise nécessaire, à fournir des services hautement spécialisés de qualité élevée

15

Maladies rares

- La Commission aide les États membres à coopérer au développement de moyens de diagnostic et de traitement, en visant à :
  - faire connaître aux professionnels de la santé les outils mis à leur disposition à l'échelle de l'Union pour les aider au diagnostic correct des maladies rares
  - faire connaître aux patients, aux professionnels de la santé et aux organismes responsables du financement de soins de santé les possibilités offertes par le règlement (CE) n 883/2004 pour le transfert de patients atteints de maladies rares vers d'autres États membres même pour des diagnostics et des traitements qui ne sont pas disponibles dans l'État membre d'affiliation

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LA DIRECTIVE 2011/24/UE SUR LE TERRAIN

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Stats soins transfrontaliers

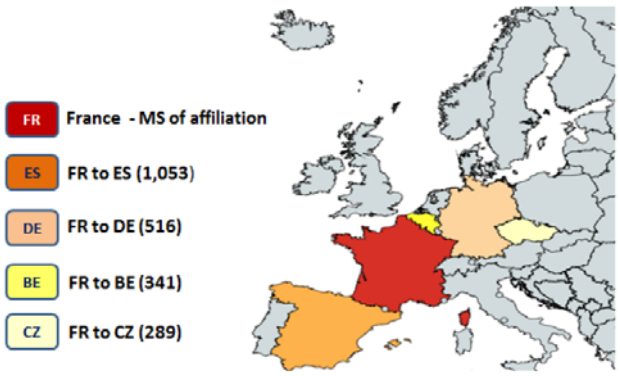
3.4 Patient Mobility with Prior Authorisation – time taken & reimbursement made

Country of affiliation	Maximum time for processing (Y/N)	Maximum time	Average Processing time (days)	aggregated amount reimbursed	in Euro
Austria	Y	5	3	no data	no data
Belgium	Y	45	No data	14,962.75	14,962.75
Bulgaria	Y	63	255	4,032.00	2,062.00
Croatia	Y	60	30	3,000.00	396.00
Cyprus	Y	60	35	21,513.44	62,712.00
Czech Republic	N/A	N/A	N/A	N/A	N/A
Denmark	Y	10	19.4	446,735.25	59.983.17
Estonia	N/A	N/A	N/A	N/A	N/A
Finland	y	14	No data	no data	no data
France	no data	no data	No data	21,750,698.70	21,750,698.70
Germany	no data	no data	No data	no data	no data
Greece	N/A	N/A	60	no data	no data
Hungary	no data	no data	No data	no data	no data
Ireland	y	30	24.9	1,752,132.01	1,752,132.01
Italy	Y	30	11.2	383,369.64	383,369.64
Latvia	Y	30	No data	no data	no data
Lithuania	N/A	N/A	N/A	N/A	N/A
Luxembourg	N	N/A	40	no data	no data
Malta	N	N/A	4	4,951.47	4,951.47
Netherlands	N	N/A	N/A	N/A	N/A
Poland	y	30	No data	0.00	0.00
Portugal	Y	35	No data	no data	no data
Romania	Y	5	3	no data	no data
Slovakia	Y	15	56	375,549.96	375,549.96
Slovenia	Y	60	34	796.23	796.23
Spain	Y	45	17	37,859.32	37,859.32
Sweden	no data	no data	No data	no data	no data
UK	Y	20	11,375	240,401.00	269,439.00
Norway	N/A	N/A	N/A	N/A	N/A
Iceland	no data	no data	No data	no data	no data
TOTAL					24,654,929.08

18

Stats soins transfrontaliers

Figure 5 Mobility from France with Prior Authorisation



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Croatia	0	1	0
Cyprus	13	0	0
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Estonia	N/A	N/A	N/A
Finland	N/A	N/A	N/A
France	no data	no data	no data
Germany	no data	no data	no data
Greece	3	0	0
Hungary	0	0	0
Ireland	197	0	0
Italy	66	19	9
Latvia	0	0	0
Lithuania	N/A	N/a	N/A
Luxembourg	no data	no data	no data
Malta	2	0	0
Netherlands	N/A	N/A	N/A
Poland	1	0	0
Portugal	1	1	0
Romania	0	0	0
Slovakia	156	42	0
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Réseaux européen de référence

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- Exemple : **Réseau européen de référence** pour les maladies osseuses / ERN on bone disorders (BOND)

> ”The network will develop guidelines, leading to the development and dissemination of best practice. As new therapeutics are developed, the network will work to ensure rapid access to studies for affected patients. BOND will enable skill development through eHealth and telemedicine platforms, alongside working visits, training courses and dissemination activities. The network aims to reduce time to diagnosis with fewer inappropriate tests, more accurate diagnosis and new viable treatments to be available within 2 to 3 years”.

21

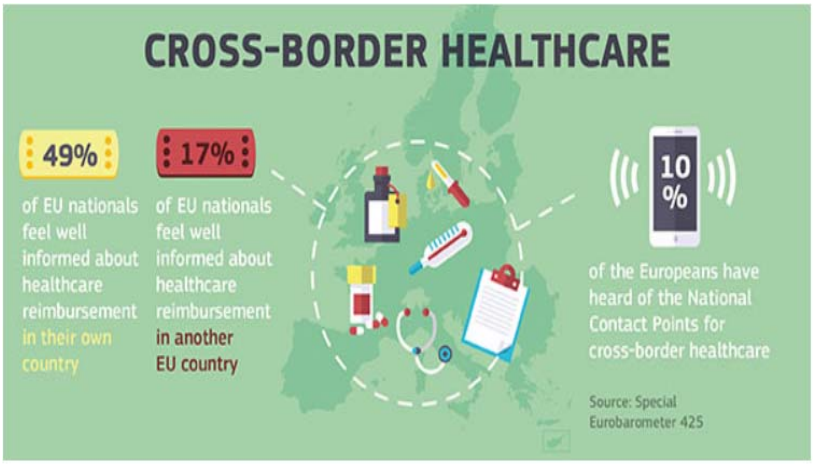
Points de contact nationaux

- Près de cinq ans après la mise en œuvre de la directive, la sensibilisation des patients à leurs droits et aux possibilités d'accès aux services de santé à l'étranger et à l'existence des PCN est encore faible
- les informations sur les droits des patients, les normes de qualité et de sécurité, et le remboursement des coûts de soins de santé hors frontière nécessitent une attention et une amélioration supplémentaires
- L'accès aux informations pour les patients entrant est en général moins complet que celui des patients sortant

Source : **Final report - Study on cross-border health services: enhancing information provision to patients**

22

Accessibilité de l'information



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conclusion

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24

COORDINATION DES SYSTEMES DE SECURITE SOCIALE

Règlements (CE) 883/2004 et 987/2009 du 29 avril 2004 portant sur la coordination des systèmes de sécurité sociale

25

Aides à la dépendance

- Les prestations de dépendance peuvent avoir essentiellement pour objet de compléter les prestations de l'assurance maladie, à laquelle elles sont d'ailleurs liées sur le plan de l'organisation, afin d'améliorer l'état de santé et la vie des personnes dépendantes.
- Dans ces conditions, et même si elles présentent des caractéristiques qui leur sont propres, elles doivent être regardées comme des «**prestations de maladie** » au sens du règlement 1408/71 (883/2004)
- Prestations de maladie en espèces ou en nature ?
  - **En espèces** (« aide financière qui permet d'améliorer globalement le niveau de vie des personnes dépendantes, de manière à compenser les surcoûts entraînés par l'état dans lequel elles se trouvent ») : exportable hors de l'Etat d'assurance (prohibition des clauses de résidence)
  - **En nature** (« prestations consistant dans une prise en charge ou un remboursement de frais d'établissement spécialisé occasionnés par l'état de dépendance de l'intéressé ») : versement, à la charge finale de l'Etat d'affiliation, des prestations du lieu de résidence ou de séjour, comme si le bénéficiaire y était affilié

La directive 2011/24 n'est pas applicable aux soins de longue durée !!

26

Aides à la dépendance

- Une assurance qui ouvre droit à la prise en charge, totale ou partielle, de certaines des dépenses entraînées par l'état de dépendance de l'assuré telles que les **soins prodigués à domicile, dans les centres ou établissements spécialisés, l'achat d'équipements nécessaires à l'assuré, la réalisation de travaux dans son logement**, ainsi qu'au versement d'une **aide financière mensuelle permettant à l'assuré de choisir le mode d'assistance** de son choix et, par exemple, de rétribuer, sous une forme ou sous une autre, les tierces personnes qui l'assistent, est une **prestation de maladie en espèces** au sens du règlement 1408/71 (883/2004)
  - Cette prestation doit être versée par le pays concerné (Allemagne) aux personnes qui y sont assurées sociales, même si elles résident en France (CJCE 5 mars 1998, aff.C-160/96, Molenaar)
  - La condition de résidence en Allemagne pour bénéficier des soins est incompatible avec le règlement
  - Des cotisations sociales doivent être acquittées en Allemagne

27

Aides à la dépendance

- Une allocation de soins («Pflegegeld») qui assure, sous forme d'une **contribution forfaitaire**, une aide et une assistance aux personnes dépendantes afin d'améliorer leurs chances de mener une vie autonome et conforme à leurs besoins, est une prestation de maladie en espèces au sens du règlement 1408/71 (883/2004)
  - Le titulaire d'une pension de retraite autrichienne, qui réside en Allemagne, peut recevoir la Pflegegeld autrichienne (CJCE 8 mars 2001, C-215/99, Jauch)

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Aides à la dépendance

- Une allocation de dépendance consistant dans le **versement d'une somme d'argent à titre de remboursement de frais**, est une prestation de maladie en nature
  - L'assuré social bénéficie donc du versement, dans l'État de résidence, des prestations en nature équivalentes (à la charge de l'Etat d'affiliation), mais pas de l'exportation de la prestation de l'Etat d'affiliation (CJCE 12 juillet 2012, aff.C-562/10, Commission c/ Allemagne - plainte, introduite contre l'administration allemande par un couple de résidents allemands ayant séjourné deux mois en Espagne et relative au remboursement des prestations de soins et de location de matériel de santé qui leur a été accordé)
  - …Quid si une telle prestation en nature n'existe pas dans l'Etat de résidence ? Le droit de l'Union [art. 21 TFUE + libre prestation des services] est impuissant à contraindre l'Etat d'assurance à verser ses prestations hors de son territoire = les règlements de coordination ne permettent pas de garantir qu'un déplacement ne se fera pas sans perte de prestation (CJCE 16 juillet 2009, aff.C-208/07, Von Chamier)

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Aides à la dépendance

- **L'aide à la personne qui consiste en la prise en charge des coûts engendrés par des activités quotidiennes d'une personne gravement handicapée**, dans le but de permettre à cette dernière, économiquement inactive, de poursuivre des études supérieures, ne saurait être considérée comme visant à améliorer l'état de santé du bénéficiaire lié au handicap et ne relève donc pas de la notion de « prestation de maladie »
  - Refuser de verser à un assuré social finlandais l'aide litigieuse au motif qu'il poursuit ses études en Estonie est une restriction à la liberté de circuler et de séjourner sur le territoire des États membres reconnue par l'article 21, paragraphe 1, TFUE (CJUE 25 juillet 2018, aff.C-679/16, A.)
    - Un handicapé mobile peut donc être mieux protégé quand la prestation de dépendance est exclue des règlements de coordination que quand elle en relève ! (cf Von Chamier)

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OPEN SOCIETY
FOUNDATIONS

Disability-related Financial Instruments in light of EU Law and the UNCRPD

Trier, 1-2 October 2018

Nataša Kokić, ENIL – European Network on Independent Living

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About ENIL

- Established in 1989;
- Brings together grassroots organisations run by disabled people, and individuals;
- Members in 47 countries across Europe;
- Advocates for control and choice for disabled people through personal assistance, peer support, barrier-free environment, housing options and technical aids;
- Our main activities: personal assistance data collection, peer support training, promoting deinstitutionalisation, EU Funds advocacy, the right to independent living, disability hate crime, 5th May – European IL Day, Freedom Drive;
- ENIL Youth Network & ECCL;
- Campaign EU Funds For Our Rights - Supported by Open Society Foundations – Mental Health Initiative - The aim is to encourage the European Commission and the Member States to improve the monitoring and complaints system, in order to ensure that Structural Funds are used to support the rights of disabled people, rather than restrict them.

AVAILABILITY AND ACCESS TO EU FINANCIAL INSTRUMENTS IN LINE WITH THE UNCRPD

General comment on Article 19 CRPD

Introduction:

13. Equality and non-discrimination are fundamental principles of international human rights law and enshrined in all core human rights instruments. In its general comment No. 5 (1994) on persons with disabilities, the Committee on Economic, Social and Cultural Rights highlights that **"segregation and isolation achieved through the imposition of social barriers" count as discrimination**. It also stresses in relation to article 11 that the right to an adequate standard of living not only includes having equal access to adequate food, accessible housing and other basic material requirements, but also the availability of support services and assistive devices and technologies fully respecting the human rights of persons with disabilities.

33. Accessibility of community facilities, goods and services, as well as the exercise of the right to inclusive, accessible employment, education and health care are essential conditions for the inclusion and participation of persons with disabilities in the community.

Various deinstitutionalization programmes have shown that the closure of institutions, regardless of their size and the relocation of inhabitants in the community, in itself is not enough. Such reforms must be accompanied by comprehensive service and community development programmes, including awareness programmes. Structural reforms designed to improve overall accessibility within the community may reduce the demand for disability-specific services.

Core elements

38. h) To **use any available funding**, including regional funding and funding for development cooperation, **to develop inclusive and accessible independent living services**.

Obligation to protect:

51. States parties should ensure that **public or private funds are not spent on maintaining, renovating, establishing building or creating any form of institution or institutionalization**. Furthermore, States parties must ensure that private institutions are not established under the guise of “community living”.

General comment on Article 5 CRPD (equality and non-discrimination)

58. Institutionalization is discriminatory as it demonstrates a failure to create support and services in the community for persons with disabilities, who are forced to relinquish their participation in community life to receive treatment.

EU financial instruments

European Structural and Investment Funds (ESIF)

Employment and Social Innovation (EaSI)

ESIF and Europe 2020

EUROPE 2020 GOALS	THEMATIC OBJECTIVES
Smarth growth	1. Strengthening research, technological development and innovation; 2. Enhancing access to, and use and quality of, ICT; 3. Enhancing the competitiveness of SMEs, of the agricultural sector (for the EAFRD) and of the fishery and aquaculture sector (for the EMFF)
Sustainable growth	1. Supporting the shift towards a low-carbon economy in all sectors; 2. Promoting climate change adaptation, risk prevention and management; 3. Preserving and protecting the environment and promoting resource efficiency; 4. Promoting sustainable transport and removing bottlenecks in key network infrastructure
Inclusive growth	1. Promoting sustainable and quality employment and supporting labour mobility; **2**. Promoting social inclusion, combating poverty and any discrimination; 3. Investing in education, training and vocational training for skills and lifelong learning; 4. Enhancing institutional capacity of public authorities and stakeholders and efficient public administration.

European Code of Conduct on Partnership

- A framework for involving partners in the programming, implementation and monitoring and evaluation of ESIF in 2014 – 2020
  - "… implies close cooperation between public authorities, economic and social partners and bodies representing civil society at national, regional and local levels throughout the whole programme cycle consisting of preparation, implementation, monitoring and evaluation." (Recital 2)
  - See Thematic Network on Partnership study on the quality of partnership

Structural Funds Regulations

- **<u>Common Provisions Regulation</u>**
  - Objective 9: Promoting social inclusion, combating poverty and any discrimination;
  - Ex ante conditionalities – a thematic conditionality (strategy for poverty reduction that includes measures for the transition from institutional to community-based care) and general conditionalities (non-discrimination and UN CRPD);

ESF

The **ESF** is Europe's main tool for promoting employment and social inclusion

Main priorities:

- To improve employment opportunities
- To promote education and life-long learning
- To enhance social inclusion and contribute to combating poverty
- To improve public services

ESF Regulation:

- Regulation (EU) No 1304/2013 of the European Parliament and of the Council of 17 December 2013 on the European Social Fund and repealing Council Regulation (EC) No 1081/2006

Preamble:

(19) In accordance with Article 10 TFEU, the implementation of the priorities financed by the ESF should contribute to combating discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation by paying particular attention to those facing multiple discrimination. Discrimination on the ground of sex should be interpreted in a broad sense so as to cover other gender-related aspects in line with the case law of the Court of Justice of the European Union. The implementation of the priorities financed by the ESF should also contribute to promoting equal opportunities. The ESF should support the fulfilment of the Union's obligation under the UN Convention on the Rights of Persons with Disabilities with regard inter alia to education, work, employment and accessibility. **The ESF should also promote the transition from institutional to community-based care. The ESF should not support any action that contributes to segregation or to social exclusion.**

Article 2 – Missions

3. The ESF shall benefit people, including disadvantaged people such as the long-term unemployed, **people with disabilities,** migrants, ethnic minorities, marginalised communities and people of all ages facing poverty and social exclusion. The ESF shall also provide support to workers, enterprises, including actors in the social economy, and entrepreneurs, as well as to systems and structures with a view to facilitating their adaptation to new challenges including reducing skill mismatches and promoting good governance, social progress, and the implementation of reforms, in particular in the fields of employment, education, training and social policies.

Article 8 - Promotion of equal opportunities and non-discrimination

The Member States and the Commission shall promote equal opportunities for all, without discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation through mainstreaming the principle of non-discrimination, as referred to in Article 7 of Regulation (EU) No 1303/2013. Through the ESF, the Member States and the Commission shall also support specific actions within any of the investment priorities referred to in Article 3, and in particular Article 3(1)(b)(iii) of this Regulation. Such actions shall aim to combat all forms of discrimination as well as to improve accessibility for persons with disabilities, with a view to improving integration into employment, education and training, thereby enhancing social inclusion, reducing inequalities in terms of educational attainment and health status, **and facilitating the transition from institutional to community-based care, in particular for those who face multiple discrimination.**

ERDF

The **ERDF** aims to strengthen economic and social cohesion in the European Union by correcting imbalances between its regions.

The ERDF focuses its investments on several key priority areas. This is known as 'thematic concentration':

- Innovation and research;
- The digital agenda;
- Support for small and medium-sized enterprises (SMEs);
- The low-carbon economy.

ERDF Regulation:

Regulation (EU) No 1301/2013 of the European Parliament and of the Council of 17 December 2013 on the European Regional Development Fund and on specific provisions concerning the Investment for growth and jobs goal and repealing Regulation (EC) No 1080/2006

Preamble:

- (15) In order to promote social inclusion and combat poverty, particularly among marginalised communities, it is necessary to improve access to social, cultural and recreational services, through the provision of small-scale infrastructure, **taking account of the specific needs of persons with disabilities and the elderly**.
- (16) Community-based services should cover all forms of in-home, family-based, residential and other community services which support the right of all persons to live in the community, with an equality of choices, and which **seek to prevent isolation or segregation from the community**.

Article 5 – Investment priorities:

- **Promoting social inclusion, combating poverty and any discrimination**, by:
- (a) investing in health and social infrastructure which contributes to national, regional and local development, **reducing inequalities** in terms of health status, promoting social inclusion through improved access to social, cultural and recreational services and **the transition from institutional to community-based services**;
- (b) providing support for physical, economic and social regeneration of deprived communities in urban and rural areas;
- (c) providing support for social enterprises;
- (d) undertaking investment in the context of community-led local development strategies.

Article 2 – Missions

3. The ESF shall benefit people, including disadvantaged people such as the long-term unemployed, **people with disabilities,** migrants, ethnic minorities, marginalised communities and people of all ages facing poverty and social exclusion. The ESF shall also provide support to workers, enterprises, including actors in the social economy, and entrepreneurs, as well as to systems and structures with a view to facilitating their adaptation to new challenges including reducing skill mismatches and promoting good governance, social progress, and the implementation of reforms, in particular in the fields of employment, education, training and social policies.

EU funds and energy efficiency

- The source of funding for institutions requires investigation - in some cases Structural Funds have been invested through Operational Programmes unrelated to reform in health and social care infrastructure, to meet other targets such as improving accessibility or **energy efficiency**.
- **Important to closely monitor energy efficiency projects** as some countries use EU funds to renovate institutions with the justification that “public sector buildings” need renovations to reduce their energy consumption.
- As in the case of energy efficiency enhancements, investments that increase accessibility in large institutions make it much more challenging to close them in the short to medium term.

Figures for 2014-2020

- Total ESIF €454 billion
  - ESF - €87 billion
  - ERDF - €197 billion

EaSI - Programme for Employment and Social Innovation

- The Employment and Social Innovation (EaSI) programme is a financing instrument at EU level to promote a high level of quality and sustainable employment, guaranteeing adequate and decent social protection, combating social exclusion and poverty and improving working conditions.

- Managed directly by the European Commission;
- It brings together three EU programmes managed separately between 2007 and 2013: PROGRESS, EURES and Progress Microfinance;
- Three axes of EaSI support:
- the modernisation of employment and social policies with the PROGRESS axis (61% of the total budget);
- job mobility with the EURES axis (18% of the total budget);
- access to micro-finance and social entrepreneurship with the Microfinance and Social Entrepreneurship axis (21% of the total budget).

- *The total budget for 2014-2020 is EUR 919,469,000 in 2013 prices.*

EaSI Regulation

Regulation (EU No 1296/2013 of the European Parliament and of the Council of 11 December 2013 on a European Union Programme for Employment and Social Innovation ("EaSI") and amending Decision No 283/2010/EU establishing a European Progress Microfinance Facility for employment and social inclusion

Article 4 - General objectives of the Programme

1. The Programme shall seek to achieve the following general objectives:

(…)

c) combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation;

Article 14 – Thematic sections and financing

The Progress axis shall support actions in one or more of the thematic sections listed in points (a), (b) and (c). Over the entire period of the Programme, the indicative breakdown of the allocation set out in point (a) of Article 5(2) between the different sections shall respect the following minimum percentages: (…)

b) social protection, social inclusion and the reduction and prevention of poverty: 50 %;

European Ombudsman initiative

- As part of her own initiative into the use of Structural Funds, the European Ombudsman issued guidelines to the European Commission on how to ensure investments are in line with the EU Charter on Fundamental Rights;
- One of the guidelines focuses on the monitoring and complaints system, and has asked the European Commission to ensure these are ‘adequate and efficient’.

European Commission's measures

Guidance on ensuring the respect of the Charter of Fundamental Rights of the European Union in the implementation of ESI Funds

Relevance of the Charter for ESIF

- The Charter is addressed to Member States (Article 51(1)) only when they are implementing EU law
- All the Member States' actions undertaken for the implementation of the applicable regulations fall within the scope of EU law

Charter applies to:

- central authorities
- regional and local authorities
- other public authorities

In the context of the ESIF: it might apply to ESIF beneficiaries, whatever their legal form is.

The Guidance document was adopted and published in OJ 2016/C 269/01:

Part I

The content, legal status and applicability of the Charter

Part II

- Implementation of ESIF and the Charter

Part III

- How to assess compliance with the Charter in the implementation of ESIF ?
- Fundamental rights checklist

Consequences of non-respect of the Charter by Member States

- Possible interruptions of payment deadlines;
- Possible suspensions of payments;
- Possible financial corrections;
- Possible infringement proceedings under Article 258 TFEU.

Commission proposals for 2021 - 2027

- Common Provisions Regulation
- ESF+
- European Regional Development Fund

Common Provisions Regulation (CPR)

Recital 5. […] Article 10 of the TFEU, including principles of subsidiarity and proportionality as set out in Article 5 of the TEU should be respected in the implementation of the Funds, taking into account the Charter of Fundamental Rights of the European Union. Member States should also respect the obligations of the UN Convention on the Rights of Persons with Disabilities and ensure accessibility […]

Article 4. Policy objectives

(d) A more social Europe implementing the European Pillar of Social Rights

Article 6. Partnership and multi-level governance

Conditionalities

Ex-ante conditionalities

Art 19 CPR 2014-2020

- Administrative capacity for the implementation and application of EU antidiscrimination law and policy in the field of ESI Funds
- Administrative capacity for the implementation and application of of the UNCRPD in the ESI Funds
- Measures to promote the shift from institutional to community-based care within the anti-poverty Strategies

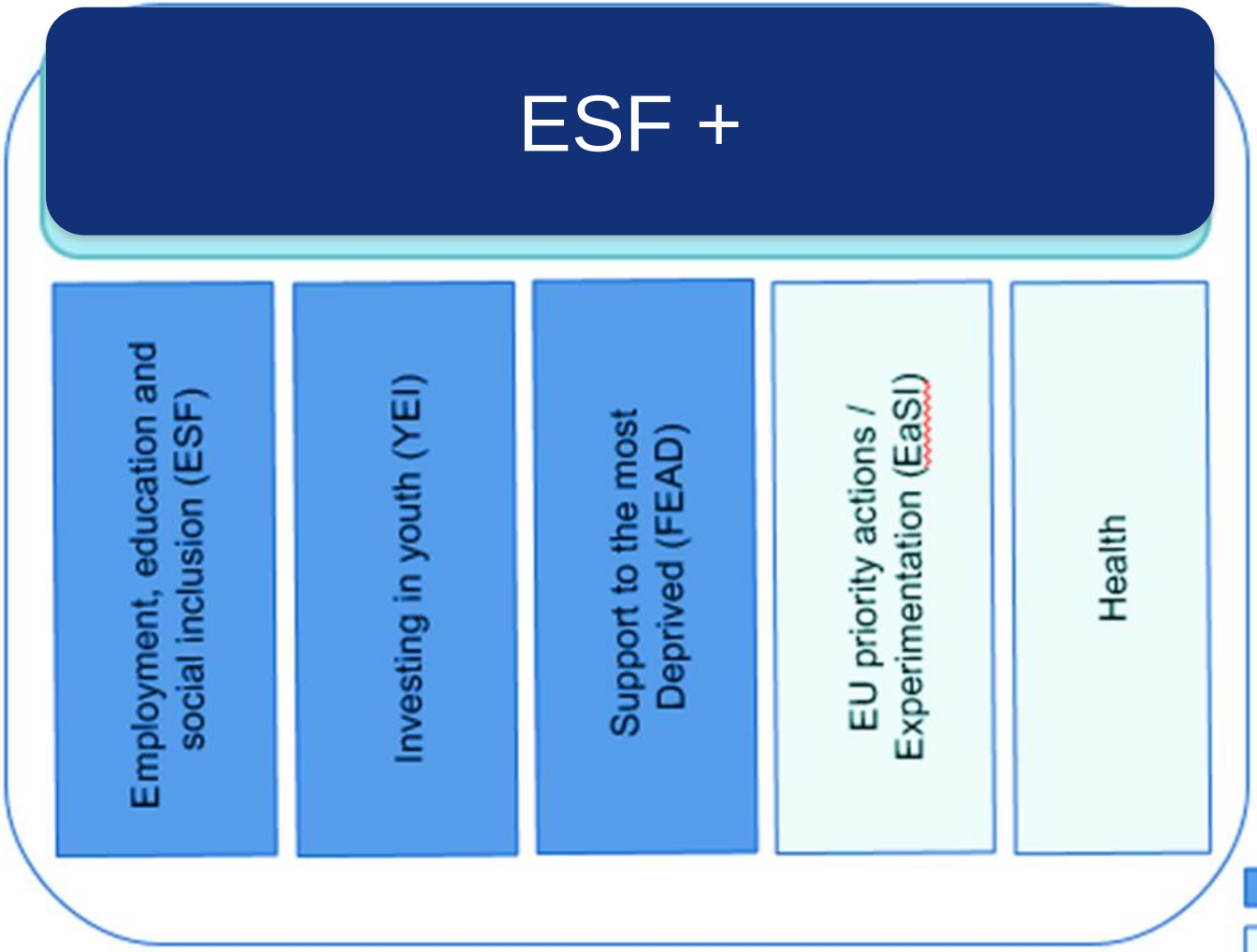
Enabling conditions

Art 11 CPR CPR 2021-2027

- Effective application and implementation of the EU charter of Fundamental Rights
- Implementation and application of the UNCRPD
- Strategic policy frameworks for social inclusion and poverty reduction & for health, including measures to promote community-based services

→ Not just set at the beginning but maintained throughout the implementation period

The ESF+: 5 funds coming together



Fundamental rights

ESF +:

- The ESF+ Regulation ensures the respect of fundamental rights and observes the principles recognised in the Charter of Fundamental Rights of the European Union. Member States must apply this Regulation in a manner consistent with these rights and principles.

ERDF:

Preamble

- (5) Horizontal principles as set out in Article 3 of the Treaty on European Union ('TEU') and in Article 10 of the TFEU, including principles of subsidiarity and proportionality as set out in Article 5 of the TEU, should be respected in the implementation of the ERDF and the Cohesion Fund, taking into account the **Charter of Fundamental Rights of the European Union.**

CPR:

- By introducing an enabling condition to ensure the respect of the Charter of Fundamental Rights of the EU, this Regulation will have a positive impact on the respect and protection of all fundamental rights in the managements of all seven funds. Respect for the rule of law is covered in a self-standing regulation based on Article 322 TFEU.

ENIL's position

Common Provisions Regulation (CPR):

General comments:

- **Fundamental rights** - Commitment to the Fundamental Rights Charter and the rule of law are only useful when accompanied by a proper monitoring and complaints system. Recital 5 refers to the need "to respect the obligations of the UNCRPD. General comments should be used by the European Commission and the Member States during the programming, implementation, monitoring and evaluation of EU funds.
- **Simplification** - While fewer controls and less administrative burden are also welcome innovations, this should not mean that there will be less oversight of how EU funds are used. On the contrary, a robust system is needed in the Member States to prevent investment in the projects that do not comply with the national and EU law and policies on fundamental rights and social inclusion.
- **Availability of data** - When it comes to projects that claim to promote the transition from institutional to community-based care', the data collected should demonstrate the extent to which persons with disabilities are able to live independently, included in the community (in line with Article 19 CRPD).

- **Monitoring and evaluation** - The proposed system is still not sufficient to ensure effective use of ESI Funds. Strengthening the partnership principle and other provisions in the regulations, such as the use of technical assistance, are of key importance.
- **Technical assistance** – It must be used to build the capacity of civil society organisations and other independent human rights institutions to monitor ESI Funds during all stages, and to participate in projects supported by ESI Funds.
- **Enabling conditions** - The framework for monitoring the horizontal and thematic "enabling conditions" should be sufficient to establish compliance with the relevant laws, policies and strategies, and measures should be taken if the Member States fail to comply.

Specific amendments:

- Inclusion of promotion of equality between women and men and anti-discrimination (recital 5).
- Inclusion of independent monitoring of compliance by the national human rights
- institutions and civil society organisations (Annex III).

- Inclusion of measures for the shift from residential/institutional care to community-based services (Annex IV).
- Inclusion of effective systems to ensure the organisation and implementation of partnership principle (Annex X).
- **ESF +**
- Highlight the importance of facilitating the freedom of movement of persons with Disabilities (recital 32).
- Inclusion of definitions “community based services” and “people with fewer opportunities” (article 2).
- Allocation of at least 30% of MS ESF+ resources for social inclusion (article 7)
- Highlight the importance of cooperation between Managing authorities and civil society organisations and social partners (article 8).
- Highlight that actions that contribute to any form of segregation are not eligible for funding (article 20).
- Underlining that audit of operations shall cover alignment of policy and funding (article 22)

ERDF

- Underlining that investments into infrastructure do not contribute to any form of segregation (article 2)

CASE STUDY: USING EU STRUCTURAL AND INVESTMENT FUNDS IN THE FIELDS OF DISABILITY FUNDS

Institutionalisation vs. IL

How SF are commonly used	How SF should be used
Renovating/modernising institutions	Developing alternatives in the community that facilitate IL (infrastructure and support, such as personal assistance)
Building new institutions	Developing alternatives in the community that facilitate IL (infrastructure and support, such as personal assistance)
Building group homes or living centres	Increasing the social housing stock, purchasing regular apartments and houses in the community, making apartments and houses in the community accessible
Funding special/parallel services (day centres, sheltered employment, special schools)	Making mainstream services accessible and available to disabled people (employment, education, childcare, health, transport etc.)

Failure to comply with the thematic *ex ante* conditionality on DI

Concern: To date, there is slow progress in some MS in establishing strategies that reflect a clear commitment to attaining the goal of independent living.

- Calls for proposals and plans not in line with Article 19 CRPD; process of DI consists of moving people from large into small institutions (Bulgaria, Hungary);
- No change in by-laws that regulate how services are provided (Croatia);
- Lack of coordination between municipalities (Lithuania), or between ESF and ERDF (Slovakia);
- No plans for DI in place, or plans fail to ensure that all public investment will go towards CBS (Greece, Slovakia);
- Significant delays in launching DI calls (Slovakia, Croatia, CZ, Slovenia, Romania).

Recommendations 1 - 3

1. Provide training on the General Comment on Article 19
   - Should target all DGs;
   - To be developed and delivered by organisations promoting IL and those with lived experience;
2. Ensure compliance with the CRPD
   - Develop guidance based on the General Comment on Article 19
3. Review *ex ante* conditionalities for EU Funding post 2020
   - Require comprehensive strategies;
   - Develop means of evaluating the strategies.

Investments that perpetuate the segregation and isolation of disabled people

Concern: ESI Funds continue to support projects that exclude disabled people from community life, rather than promote their social inclusion.

- Development of small group homes with no significant difference in the provision of care from institutions (Bulgaria, Romania, Hungary, Slovenia, Portugal);
- Adults with disabilities placed into foster homes (Croatia);
- Failure to move ahead with the closure of large residential institutions (Greece, Hungary).

Recommendation 4

Take action to prevent the inappropriate use of ESI Funds:

- EC should investigate cases of potential ‘misuse’ of ESI Funds and intervene in all cases when projects or plans fail to comply with Article 19 CRPD;
- Make clear to MS that ESI Funds must not be used for projects that exclude disabled people from society;
- Work with organisations promoting IL.

Inadequate monitoring and complaints procedure

Concern: The existing monitoring systems – in the MS and at EU level - are not robust enough to prevent the use of ESI Funds for projects that perpetuate the social exclusion and segregation of disabled people.

- More information needed from MS on their use of ESI Funds;
- MCs have key role but need support to enable them to exercise their functions effectively;
- Action needed to ensure that disabled people are involved in monitoring the use of ESI Funds;
- Although MS are required to establish an effective complaints procedure, there is little clarity on how this obligation is to be met;
- Insufficient information provided to the general public on the ESI Funds monitoring mechanisms and there is little opportunity for CSOs to provide feedback on how projects funded by ESI Funds are being implemented in practice.

Recommendation 5

Improve the monitoring mechanisms for ESI Funds:

- Put in place a system to improve how ESI Funds investments are monitored;
- Enable access to relevant information;
- Increase the capacity of CSOs to take part in different stages of ESI Funds use.

More attention needed to evaluate ESI Funds' impact on IL

Concern: Once programmes have been selected for funding, not enough attention is paid to their impact on the final beneficiaries, their quality of life and the degree of their social inclusion and participation in community.

- Involvement of CSOs promoting independent living in MCs should be significantly improved in many MS (good examples in Latvia and Slovakia);
- Promising projects include using the ESF to support personal assistance (for example, in Croatia), although a full evaluation is needed to establish compliance with Article 19 CRPD;
- Other projects, which claim to support independent living also require a comprehensive evaluation.

Recommendation 6

Involve disabled people in the evaluation of the support they receive:

- Process for evaluating projects intended to promote IL must take into account experiences of those who 'benefit' from ESI Funding.

Barriers to achieving meaningful participation and lack of information

Concern: Disabled people and their organisations are still largely excluded from the process of ESI Funds planning, implementation, monitoring and evaluation. There is little evidence of the use of ESI Funds to facilitate access to the right to IL.

- Exclusion from the Monitoring Committees;
- Lack of capacity;
- Difficulties in accessing information (Hungary);
- Legal capacity and failure to build on good practice (Romania);
- Co-financing requirement (Slovakia);
- Closed calls and vetting (Greece).

Recommendation 7

Enhance the implementation of the partnership principle:

- EC to improve monitoring of CSO engagement at the national level;
- Consider how to involve the most marginalised groups of disabled people;
- Encourage MS to publicise information about projects funded.

Continued investment of national funds into institutional care

Concern: MS continue placing disabled people into institutional care, by building new state-funded residential care facilities. This is not seen as a 'European problem' despite the fact the EU and all but one MS are party to the CRPD.

- Continued investment of national funds into institutional care and of the lack of EU support to facilitate IL (Belgium, France, Germany, the Netherlands, Slovenia, Spain);
- Some MS focus on employment and labour market reintegration, but even then disabled people can be excluded (the Netherlands, Belgium);
- Lack of DI strategies (Germany, France, Belgium);
- Lack of knowledge on using ESI Funds to support DI.

Recommendation 8

Encourage more Member States to use ESI Funds for deinstitutionalisation:

- All MS that have not yet closed their long-stay residential institutions for disabled people should have DI as one of their investment priorities post 2020.

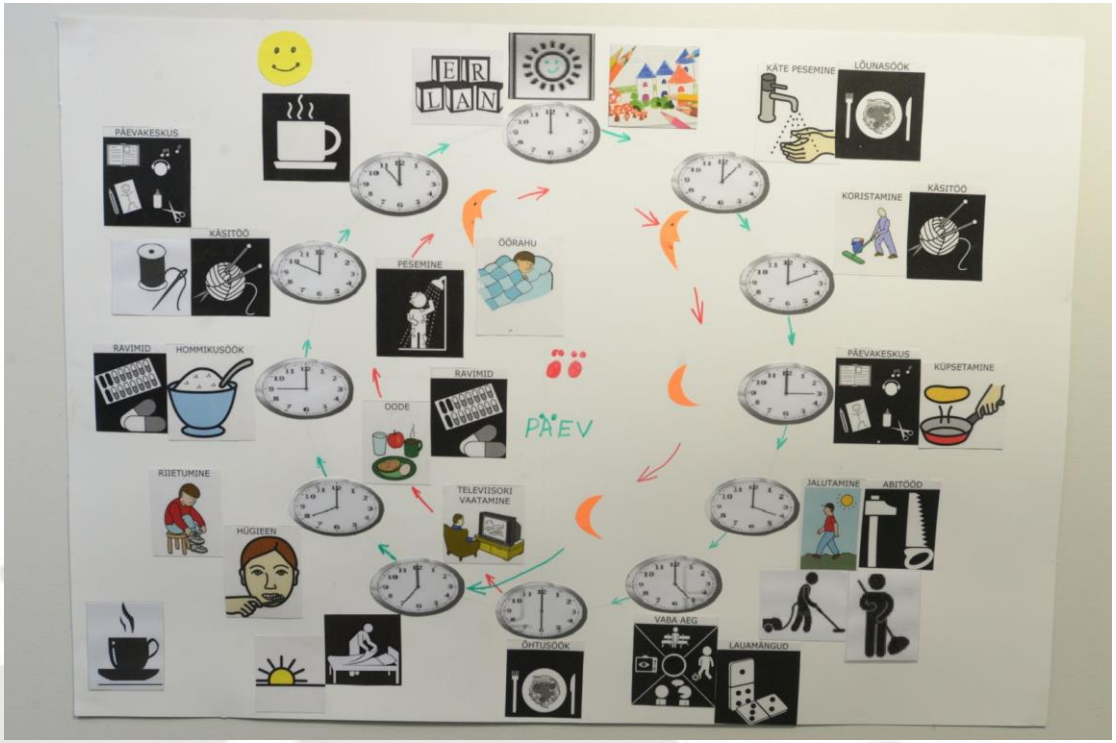
Areas requiring action

1. Failure to comply with the **thematic ex ante conditionality** on deinstitutionalisation;
2. Investments that perpetuate the **segregation and isolation** of disabled people;
3. Inadequate **monitoring and complaints** procedures;
4. More attention needed to evaluate ESI Funds' **impact** on Independent Living;
5. Barriers to achieving **meaningful participation** and **lack of information** about the use of ESI Funds;
6. Continued **investment of national funds** into institutional care.

Estonia (2007-2013)

Sinimäe village (*Sinimäe alevik*)

Sinimäe village (*Sinimäe alevik*)



10 persons per service unit and 6 service units = 60 persons total

Daily plan for the customers living in the house, which sets out the time for meals, daily routines (showering, cleaning, dressing etc), work and free time activities (day center, exercising, handicraft etc).

Home rules (extracts)

“I follow the daily plan of the home/---/ During the night I stay in the Home”.

“I know that in the territory of the home it is prohibited to consume alcohol/---/”

“If agreed with the occupational therapist, I can use my own things in my own room: television, radio and other technical equipment as well as furniture.”

“If agreed with the occupational therapist, I have an opportunity to use the Home’s telephone 10 minutes per week.”

“I am aware, that the Home can end the contract with me before it has expired, if I break the rules more than once.”

Portugal (2014-2020)

1 – Azores Government (http://www.azores.gov.pt/Portal/pt/entidades/srss-drss/textoImagem/ACORES-09-4842-FEDER-000010-_Construcao_do_Lar_Residencial_dos_Valados.htm)


Governo dos Açores
Associação Seara do Trigo
Lar Residencial
Inaugurado no dia 7 de dezembro de 2015, sendo
Presidente do Governo Regional dos Açores
Vasco Alves Cordeiro
e Presidente da Direção da Seara do Trigo
Mário Jorge Sampaio de Carvalho
AÇORES
2020

2

3

Hungary (2014-2020)

- Call for Proposals on Human Resources Development Operational Programme 2.2.2 – 17. Conversion of institutional supply to community-based services – replacing institutional places (EFOP-2.2.2.-17) – projects which affect 2,500 people with disabilities and are valued at nearly 24 billion HUF (76 million EUR), and will result in further segregation of people with disabilities in hundreds of new mini-institutions.
- ENIL, the Validity Foundation, and the Hungarian Civil Liberties Union ask the government to suspend the projects currently under implementation and thoroughly redesign the process: Press release: http://enil.eu/news/hungarian-government-must-suspend-redesign-deinstitutionalisation-projects-affecting-2500-people-disabilities/

- # Problems detected:

- Many of the group homes which will be built, will be located away from cities in sparsely inhabited rural settlements, thus further ostracising people with disabilities. Many of the settlements chosen lack public services, have aging communities and declining populations.
- Some group homes will be built on flood plains; on inaccessible, industrial zones; swampy-reedy areas or near a sewage disposal plant.
- In many cases, group homes will be built within the grounds of current large institutions or in the immediate proximity of them Residents of the newly built homes will be transported by minibuses to so-called Service Centres which will, in many cases, be established in the area of the former large institutions or in some cases inside of them. People will still eat and be cared for as previously, in an institutional setting.
- The new residential homes will function as mini-institutions, denying people their independence: they won't be able to decide where and with whom they live, choose their careers, or make choices about their daily routine.

Useful resources

- ENIL – Briefing on the use of EU Funds for Independent Living: http://enil.eu/wp-content/uploads/2018/04/EU-Funds-Briefing_web0903.pdf
- ENIL Briefing - Towards a more effective monitoring and complaints system: http://enil.eu/wp-content/uploads/2017/07/OurRightsCampaign-Briefing_FINAL.pdf
- ENIL Report Working Together to Close the Gap: http://www.enil.eu/wp-content/uploads/2016/06/Working-Together-to-Close-the-Gap-web.pdf
- ENIL Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional care to Community Living: http://community-living.info/wp-content/uploads/2014/02/Structural-Fund-Briefing-final-WEB.pdf
- ENIL Myth Buster on Independent Living: http://www.enil.eu/wp-content/uploads/2014/12/Myths-Buster-final-spread-A3-WEB.pdf
- General Comment on Article 19: https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en

- Common provisions regulation (CPR): http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:32013R1303
- ERDF Regulation: https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32013R1301
- ESF Regulation: https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A32013R1304
- Open Data Portal – DG Regio: https://cohesiondata.ec.europa.eu/
- Guidance on ensuring the respect for the Charter of Fundamental Rights of the European Union when implementing the European Structural and Investment Funds: http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.C_.2016.269.01.0001.01.ENG&toc=OJ:C:2016:269:TOC
- Commission delegated Regulation (EU) of 7.1.2014 on the European code of conduct on partnership in the framework of the European Structural and Investment Funds: http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L_.2014.074.01.0001.01.ENG
- ESF in your country: http://ec.europa.eu/esf/main.jsp?catId=45&langId=en
- ERDF: http://ec.europa.eu/regional_policy/en/atlas/managing-authorities/
- ESIF guidance: http://ec.europa.eu/regional_policy/en/information/legislation/guidance/
- Partnership Agreements: https://ec.europa.eu/info/publications/partnership-agreements-european-structural-and-investment-funds_en

Thank you for your attention!

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OPEN SOCIETY FOUNDATIONS

Les instruments financiers liés au handicap à la lumière du droit de l'UE et de la CDPH

Trêves, 1-2 octobre 2018

Nataša Kokić, ENIL – Réseau européen pour la vie autonome

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À propos de l'ENIL

- Fondation en 1989
- Association d'organisations de terrain gérées par des personnes handicapées et de particuliers
- Membres dans 47 pays en Europe
- Objectifs : les personnes handicapées doivent pouvoir diriger leur vie et faire leurs propres choix grâce à une aide personnelle, au soutien de leurs pairs, à un environnement accessible, à des possibilités de logement et à des aides techniques
- Activités principales : collecte de données sur l'aide personnelle, formation au soutien par les pairs, promotion de la désinstitutionnalisation, démarches auprès des Fonds de l'UE, droit à une vie autonome, crime haineux fondé sur le handicap, 5 mai - Journée européenne de la vie autonome, Freedom Drive
- ENIL Youth Network et ECCL
- Campagne EU Funds for our rights - Avec le soutien de l'Open Society Foundations - Initiative sur la santé mentale - Objectif : amener la Commission européenne et les États membres à améliorer le système de suivi et de plainte afin d'assurer que les Fonds structurels sont utilisés en faveur des droits des personnes handicapées et n'y font pas obstacle

DISPONIBILITÉ ET ACCESSIBILITÉ DES INSTRUMENTS FINANCIERS DE L'UE DANS LE RESPECT DE LA CDPH

Observation générale sur l'article 19 de la CDPH

Introduction :

13. L'égalité et la non-discrimination sont des principes fondamentaux du droit international des droits de l'homme et elles sont consacrées par tous les instruments fondamentaux relatifs à ces droits. Dans son observation générale nº 5 (1994) sur les personnes souffrant d'un handicap, le Comité des droits économiques, sociaux et culturels souligne que **« la ségrégation et l'isolement imposés […] socialement » constituent des formes de discrimination**. Il souligne également, dans le cadre de l'article 11 du Pacte international relatif aux droits économiques, sociaux et culturels, que le droit à un niveau de vie suffisant suppose non seulement l'accès à une alimentation suffisante et à un logement accessible dans des conditions d'égalité ainsi que la satisfaction des autres besoins matériels de base, mais aussi la disponibilité de services d'appui et d'équipements et de technologies d'assistance qui soient pleinement respectueux des droits fondamentaux des personnes handicapées.

33. L'accessibilité des installations, biens et services sociaux, ainsi que l'exercice du droit à l'emploi, à l'éducation et à des soins de santé dans le respect des principes d'inclusion et d'accessibilité sont des conditions essentielles à l'inclusion des personnes handicapées dans la société et à leur participation.

Divers programmes de désinstitutionalisation ont montré que la fermeture des établissements spécialisés, indépendamment de leur taille et des modalités de réinsertion des personnes qu'ils accueillaient, ne suffit pas en elle-même à la réalisation de ces objectifs. De telles réformes doivent s'accompagner de la mise en place d'un ensemble complet de services et du déploiement de programmes de développement communautaire, notamment de programmes de sensibilisation. Les réformes de fond visant à améliorer l'accessibilité globale dans la société peuvent réduire la demande de services spécifiques au handicap.

Éléments essentiels

38. h) **Utiliser tous les crédits disponibles**, y compris les financements régionaux et les fonds de coopération pour le développement, **pour mettre en place des services inclusifs et accessibles d'aide à l'autonomie de vie**.

Obligation de protéger

51. Les États parties devraient veiller à ce que **les financements publics ou privés ne soient pas alloués au fonctionnement, à la rénovation ou à la construction d'institutions ni à la création d'établissements de placement analogues**. En outre, les États parties doivent veiller à ce que des institutions privées ne soient pas établies sous couvert de « vie communautaire ».

Observation générale sur l'article 5 de la CDPH (égalité et non-discrimination)

58. Le placement en institution est discriminatoire en ce qu'il est révélateur d'une incapacité à créer, dans la société, des services d'appui aux personnes handicapées, qui sont contraintes de renoncer à leur participation à la vie de la société pour recevoir un traitement.

Instruments financiers de l'UE

Fonds structurels et d'investissement européens (Fonds ESI)

Programme de l'UE pour l'emploi et l'innovation sociale (EaSI)

Fonds ESI et Europe 2020

OBJECTIFS EUROPE 2020	OBJECTIFS THÉMATIQUES
Croissance intelligente	1. Renforcer la recherche, le développement technologique et l'innovation 2. Améliorer l'accès aux TIC, leur utilisation et leur qualité 3. Renforcer la compétitivité des PME, du secteur agricole (pour le Feader) et du secteur de la pêche et de l'aquaculture (pour le FEAMP)
Croissance durable	1. Soutenir la transition vers une économie à faible émission de carbone dans tous les secteurs 2. Promouvoir l'adaptation au changement climatique et la prévention et la gestion des risques 3. Préserver et protéger l'environnement et encourager l'utilisation rationnelle des ressources 4. Promouvoir le transport durable et supprimer les goulets d'étranglement dans les infrastructures de réseaux essentielles
Croissance inclusive	1. Promouvoir un emploi durable et de qualité et soutenir la mobilité de la main-d'œuvre **2.** Promouvoir l'inclusion sociale et lutter contre la pauvreté et toute forme de discrimination 3. Investir dans l'éducation, la formation et la formation professionnelle pour l'acquisition de compétences et l'apprentissage tout au long de la vie 4. Renforcer les capacités institutionnelles des autorités publiques et des parties intéressées et contribuer à l'efficacité de l'administration publique

Code de conduite européen sur le partenariat

- Cadre pour la participation de partenaires à la programmation, à la mise en œuvre, au suivi et à l'évaluation des Fonds ESI au cours de la période 2014-2020
  - « (...) suppose une étroite coopération entre les pouvoirs publics, les partenaires économiques et sociaux et les organisations représentant la société civile aux niveaux national, régional et local, tout au long du cycle du programme (préparation, mise en œuvre, suivi et évaluation). » (considérant 2)
  - Voir l'étude sur la qualité des partenariats du Réseau thématique des partenariats

Règlements relatifs aux Fonds structurels

- **Règlement portant dispositions communes**
  - Objectif 9 : Promouvoir l'inclusion sociale et lutter contre la pauvreté et toute forme de discrimination
  - Conditions ex ante – condition thématique (une stratégie de lutte contre la pauvreté doit comprendre des mesures pour le passage d'une prise en charge institutionnelle à une prise en charge de proximité) et conditions générales (non-discrimination et CDPH des Nations unies)

FSE

Le **FSE** est le principal instrument européen destiné à promouvoir l'emploi et l'inclusion sociale

Priorités essentielles :

- Améliorer les possibilités d'emploi
- Promouvoir l'éducation et l'apprentissage tout au long de la vie
- Accroître l'inclusion sociale et contribuer à la lutte contre la pauvreté
- Améliorer les services publics

Règlement relatif au FSE

- Règlement (UE) n° 1304/2013 du Parlement européen et du Conseil du 17 décembre 2013 relatif au Fonds social européen et abrogeant le règlement (CE) n° 1081/2006 du Conseil

Préambule :

(19) Conformément à l'article 10 du traité sur le fonctionnement de l'Union européenne, la mise en œuvre des priorités financées par le FSE devrait contribuer à la lutte contre toute discrimination fondée sur le sexe, la race ou l'origine ethnique, la religion ou les convictions, un handicap, l'âge ou l'orientation sexuelle en accordant une attention particulière aux personnes confrontées à une discrimination multiple. Il convient d'interpréter au sens large l'expression « discrimination fondée sur le sexe », de sorte à ce qu'elle englobe d'autres aspects liés au genre, conformément à la jurisprudence établie par la Cour de justice de l'Union européenne. La mise en œuvre des priorités financées par le FSE devrait également contribuer à favoriser l'égalité des chances. Le FSE devrait favoriser le respect des obligations de l'Union inscrites dans la convention des Nations unies relative aux droits des personnes handicapées, notamment en ce qui concerne l'éducation, le travail et l'emploi ainsi que l'accessibilité. **Il devrait également promouvoir le passage d'une prise en charge institutionnelle à une prise en charge de proximité. Le FSE ne devrait soutenir aucune action contribuant à la ségrégation ou à l'exclusion sociale.**

Article 2 – Missions

3. Le FSE intervient en faveur des personnes, notamment les personnes défavorisées telles que les chômeurs de longue durée, **les personnes handicapées**, les migrants, les minorités ethniques, les communautés marginalisées et les personnes de toutes les catégories d'âge victimes de la pauvreté et de l'exclusion sociale. Le FSE apporte également un soutien aux travailleurs et aux entreprises, notamment aux acteurs de l'économie sociale, aux entrepreneurs ainsi qu'aux systèmes et aux structures afin de faciliter leur adaptation aux nouveaux défis, en favorisant une mise à niveau des compétences, et il favorise la bonne gouvernance, le progrès social et la mise en œuvre de réformes, en particulier des politiques menées dans le domaine social, de l'emploi, de l'éducation et de la formation.

Article 8 – Promotion de l'égalité des chances et de la non-discrimination

Les États membres et la Commission favorisent l'égalité des chances pour tous, sans discrimination fondée sur le sexe, la race ou l'origine ethnique, la religion ou les convictions, un handicap, l'âge ou l'orientation sexuelle, par la prise en compte systématique du principe de non-discrimination à tous les niveaux, conformément à l'article 7 du règlement (UE) nº 1303/2013. Par le biais du FSE, les États membres et la Commission soutiennent également des actions spécifiques menées dans le cadre des différentes priorités d'investissement définies à l'article 3, et notamment à l'article 3, paragraphe 1, point b) iii), du présent règlement. Ces actions visent à lutter contre toutes les formes de discrimination et à améliorer l'accessibilité des personnes handicapées, l'objectif étant de faciliter l'intégration sur le marché du travail, dans le monde éducatif et dans le système de formation, ainsi que, par là même, d'améliorer l'inclusion sociale, de réduire les inégalités sur le plan des niveaux de qualification et de l'état de santé, **et de faciliter le passage d'une prise en charge institutionnelle à une prise en charge de proximité, notamment pour les personnes confrontées à une discrimination multiple**.

FEDER

Le **FEDER** vise à renforcer la cohésion économique et sociale au sein de l'Union européenne en corrigeant les déséquilibres entre ses régions.

Les investissements du FEDER mettent l'accent sur plusieurs domaines prioritaires, ce qu'on appelle la « concentration thématique » :

- Innovation et recherche
- Transformation numérique
- Soutien aux petites et moyennes entreprises (PME)
- Économie à faible émission de carbone

Règlement relatif au FEDER

Règlement (UE) nº 1301/2013 du Parlement européen et du Conseil du 17 décembre 2013 relatif au Fonds européen de développement régional et aux dispositions particulières relatives à l'objectif « Investissement pour la croissance et l'emploi », et abrogeant le règlement (CE) nº 1080/2006 du Conseil

Préambule :

- (15) Afin de promouvoir l'inclusion sociale et de lutter contre la pauvreté, en particulier dans les communautés marginalisées, il est nécessaire d'améliorer l'accès aux services sociaux, culturels et récréatifs, en mettant à disposition des infrastructures de petite échelle, **qui tiennent compte des besoins spécifiques des personnes handicapées et des personnes âgées**.
- (16) Les services de proximité devraient couvrir toutes les formes de services à domicile, de services fournis par les familles, de services en institution et autres services collectifs qui soutiennent le droit de chacun à vivre dans la communauté, avec une égalité de choix, et qui **visent à empêcher l'isolement ou l'exclusion de la communauté**.

Article 5 – Priorités d'investissement

- **Promouvoir l'inclusion sociale, lutter contre la pauvreté et toute forme de discrimination** :
- a) en investissant dans des infrastructures sociales et sanitaires contribuant au développement national, régional et local, en **réduisant les inégalités** sur le plan de l'état de santé, en favorisant l'inclusion sociale par un accès amélioré aux services sociaux, culturels et récréatifs et **le passage de services institutionnels à des services de proximité** ;
- b) en fournissant un soutien à la revitalisation physique, économique et sociale des communautés défavorisées en zones urbaines et rurales ;
- c) en fournissant un soutien aux entreprises sociales ;
- d) en effectuant des investissements dans le contexte de stratégies de développement local mené par les acteurs locaux.

Article 2 – Missions

3. Le FSE intervient en faveur des personnes, notamment les personnes défavorisées telles que les chômeurs de longue durée, **les personnes handicapées**, les migrants, les minorités ethniques, les communautés marginalisées et les personnes de toutes les catégories d'âge victimes de la pauvreté et de l'exclusion sociale. Le FSE apporte également un soutien aux travailleurs et aux entreprises, notamment aux acteurs de l'économie sociale, aux entrepreneurs ainsi qu'aux systèmes et aux structures afin de faciliter leur adaptation aux nouveaux défis, en favorisant une mise à niveau des compétences, et il favorise la bonne gouvernance, le progrès social et la mise en œuvre de réformes, en particulier des politiques menées dans le domaine social, de l'emploi, de l'éducation et de la formation.

Les fonds de l'UE et l'efficacité énergétique

- Les sources de financement des institutions doivent être examinées. Dans certains cas, les Fonds structurels ont été investis par le biais de programmes opérationnels qui n'avaient aucun lien avec une réforme des infrastructures sociales et sanitaires, pour atteindre d'autres objectifs tels que l'amélioration de l'accessibilité ou de l'**efficacité énergétique**.
- Il est **important de surveiller étroitement les projets relatifs à l'efficacité énergétique** car certains pays utilisent les fonds européens pour rénover leurs établissements au motif que les « bâtiments du secteur public » doivent être rénovés pour réduire leur consommation d'énergie.
- De la même manière qu'après une augmentation de l'efficacité énergétique, il est beaucoup plus difficile de fermer de grands établissements après la réalisation d'investissements qui ont amélioré leur accessibilité.

Chiffres pour la période 2014-2020

- Total des Fonds ESI : 454 milliards d'euros
  - FSE : 87 milliards d'euros
  - FEDER : 197 milliards d'euros

EaSI – Programme pour l'emploi et l'innovation sociale

- Le programme pour l'emploi et l'innovation sociale (EaSI) est un instrument de financement européen visant à promouvoir un niveau élevé d'emplois durables et de qualité, à garantir une protection sociale correcte et adéquate, à lutter contre la pauvreté et l'exclusion sociale et à améliorer les conditions de travail.

- Géré directement par la Commission européenne
- Il regroupe trois programmes de l'UE, gérés séparément de 2007 à 2013 : PROGRESS, EURES et l'instrument de microfinancement Progress
- Trois volets soutenant :
- la modernisation des politiques sociales et de l'emploi : volet PROGRESS (61 % du budget) ;
- la mobilité professionnelle : volet EURES (18 % du budget) ;
- l'accès au microfinancement et à l'entrepreneuriat social, avec le volet Microfinance et entreprenariat social (21 % du budget).

- *Le budget total pour 2014-2020 s'élève à 919 469 000 EUR (prix de 2013).*

Règlement relatif au programme EaSI

Règlement (UE) nº 1296/2013 du Parlement européen et du Conseil du 11 décembre 2013 établissant un programme de l'Union européenne pour l'emploi et l'innovation sociale (EaSI) et modifiant la décision nº 283/2010/UE instituant un instrument européen de microfinancement Progress en faveur de l'emploi et de l'inclusion sociale

Article 4 – Objectifs généraux du programme

1. Le programme vise à atteindre les objectifs généraux suivants :

(…)

c) lutter contre toute discrimination fondée sur le sexe, l'origine raciale ou ethnique, la religion ou les convictions, un handicap, l'âge ou l'orientation sexuelle ;

Article 14 – Sections thématiques et financement

Le volet « Progrès » soutient des actions menées au titre d'une ou de plusieurs sections thématiques énumérées aux points a), b) et c). Durant toute la durée du programme, la répartition indicative des crédits, énoncée à l'article 5, paragraphe 2, point a), entre les différentes sections respecte les pourcentages minimaux suivants : (…)

b) la protection sociale, l'insertion sociale ainsi que la réduction et la prévention de la pauvreté : 50 %

Initiative de la Médiatrice européenne

- Dans le cadre de son enquête d'initiative sur l'affectation des Fonds structurels, la Médiatrice européenne a adressé une série de recommandations à la Commission européenne pour assurer que les investissements soient conformes à la Charte des droits fondamentaux de l'UE.
- Selon la recommandation portant sur le système de suivi et de plainte, la Commission européenne devrait garantir que ce système est « approprié et efficace ».

Mesures de la Commission européenne

Orientations relatives à la garantie du respect de la Charte des droits fondamentaux de l'Union européenne lors de la mise en œuvre des Fonds ESI

Pertinence de la Charte pour les Fonds ESI

- La Charte s'adresse aux États membres uniquement lorsqu'ils mettent en œuvre le droit de l'Union (article 51, paragraphe 1).
- Toutes les mesures prises par les État membres aux fins de la mise en œuvre de la réglementation applicable relèvent du champ d'application du droit de l'Union.

La Charte s'applique :

- aux autorités centrales,
- aux autorités régionales et locales,
- aux autres autorités publiques.

Dans le contexte des Fonds ESI : elle peut s'appliquer aux bénéficiaires des Fonds ESI, quelle que soit leur forme juridique.

Les Orientations ont été adoptées et publiées au JO 2016/C 269/01 :

Partie I

Contenu, statut juridique et applicabilité de la Charte

Partie II

- Mise en œuvre des Fonds ESI et de la Charte

Partie III

- Évaluer la conformité avec la Charte dans la mise en œuvre des Fonds ESI
- Liste de contrôle des droits fondamentaux

Conséquences du non-respect de la Charte par les États membres

- Possibilité de suspension des délais de paiement
- Possibilité de suspension des paiements
- Possibilité de corrections financières
- Possibilité de procédures d'infraction au titre de l'article 258 TFUE

Propositions de la Commission pour la période 2021-2027

- Règlement portant dispositions communes
- FSE+
- Fonds européen de développement régional

Règlement portant dispositions communes (RPDC)

Considérant 5. Il convient que les principes horizontaux tels qu'énoncés (...) à l'article 10 du TFUE, notamment les principes de subsidiarité et de proportionnalité tels qu'énoncés à l'article 5 du traité UE soient respectés dans le cadre de la mise en œuvre des Fonds, en tenant compte de la Charte des droits fondamentaux de l'Union européenne. Les États membres devraient également respecter les obligations de la Convention des Nations unies relative aux droits des personnes handicapées et garantir l'accessibilité (...)

Article 4. Objectifs stratégiques

(d) Une Europe plus sociale mettant en œuvre le socle européen des droits sociaux ;

Article 6. Partenariat et gouvernance à plusieurs niveaux

Conditions

Conditions ex ante

Art. 19 du RPDC 2014-2020

- Capacités administratives pour la transposition et l'application de la législation de l'Union en matière de lutte contre la discrimination dans le domaine des Fonds ESI
- Capacités administratives pour la transposition et l'application de la CDPH dans le domaine des Fonds ESI
- Mesures d'accompagnement de la transition d'une prise en charge en institution à une prise en charge de proximité dans le cadre de la lutte contre la pauvreté

Conditions favorisantes

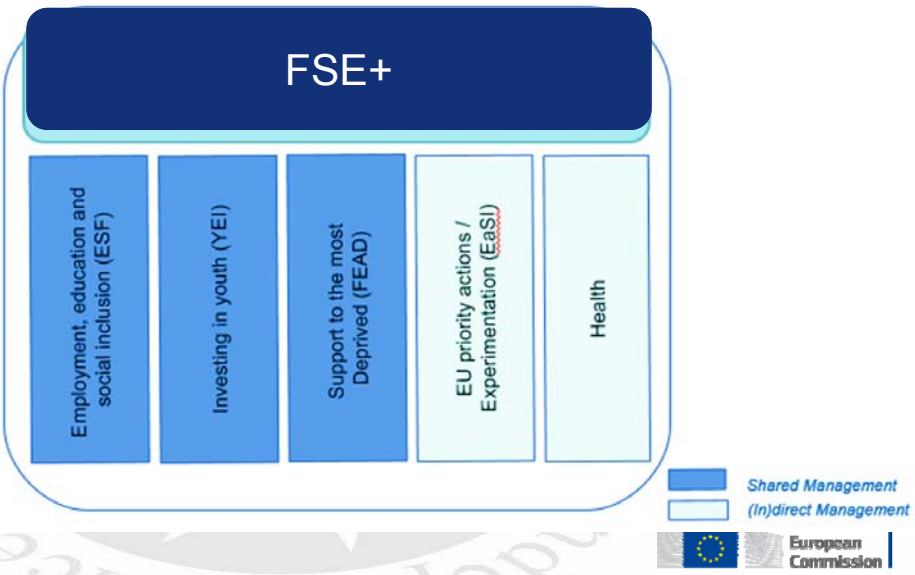
Art. 11 du RPDC 2021-2027

- Application et mise en œuvre effective de la charte des droits fondamentaux de l'UE
- Mise en œuvre et application de la CDPH
- Cadres stratégiques nationaux pour l'inclusion sociale et la réduction de la pauvreté et en matière de santé, qui comprend des mesures visant à promouvoir les services de proximité

→ Pas seulement au lancement, mais pendant toute la période de mise en œuvre

European Commission

FSE+ : rapprochement entre 5 Fonds



European Commission

Droits fondamentaux

FSE+

- Le règlement FSE+ garantit le respect des droits fondamentaux et observe les principes reconnus par la Charte des droits fondamentaux de l'Union européenne. Le présent règlement doit être appliqué par les États membres dans le respect de ces droits et principes.

FEDER

Préambule

- (5) Il convient que les principes horizontaux tels qu'énoncés à l'article 3 du traité sur l'Union européenne (ci-après le « traité UE ») et à l'article 10 du TFUE, notamment les principes de subsidiarité et de proportionnalité tels qu'énoncés à l'article 5 du traité UE, soient respectés dans le cadre de la mise en œuvre du FEDER et du Fonds de cohésion, compte tenu de la **charte des droits fondamentaux de l'Union européenne**.

RPDC

- En introduisant une condition favorisante pour garantir le respect de la Charte des droits fondamentaux de l'Union européenne, le présent règlement aura un effet positif sur le respect et la protection de tous les droits fondamentaux dans la gestion de l'ensemble des sept Fonds. Le respect de l'état de droit fait l'objet d'un règlement autonome fondé sur l'article 322 du TFUE.

ÉTUDE DE CAS : UTILISATION DES FONDS STRUCTURELS ET D'INVESTISSEMENT DE L'UE DANS LE DOMAINE DU HANDICAP

Institutionnalisation ou vie autonome

Comment les FS sont souvent utilisés	Comment les FS devraient être utilisés
Rénovation/modernisation d'établissements	Élaboration d'alternatives de proximité qui facilitent la VA (infrastructures et soutien, p. ex. assistance personnelle)
Construction de nouvelles institutions	Élaboration d'alternatives de proximité qui facilitent la VA (infrastructures et soutien, p. ex. aide personnelle)
Construction de foyers ou de lieux d'accueil collectifs	Augmentation du parc de logements sociaux, achat d'appartements et de maisons ordinaires en ville, aménagements d'appartements et de maisons en ville pour leur accessibilité
Financement de services spéciaux/parallèles (centres de jour, emplois protégés, écoles spéciales)	Accessibilité et disponibilité des services généraux pour les personnes handicapées (emploi, éducation, garde d'enfants, santé, transports, etc.)

Non-respect de la condition ex ante thématique de la désinstitutionnalisation

Problème : certains États membres progressent lentement dans l'adoption de stratégies traduisant un engagement clair pour l'objectif de la vie autonome.

- Appels à propositions et plans non conformes à l'article 19 de la CDPH - au lieu d'une désinstitutionnalisation, un transfert est opéré depuis de grands établissements vers de plus petits (Bulgarie, Hongrie)
- Pas de changement des dispositions régissant la fourniture des services (Croatie)
- Manque de coordination entre les municipalités (Lituanie) ou entre le FSE et le FEDER (Slovaquie)
- Pas de plans de désinstitutionnalisation définis, ou pas de garantie dans les plans que tous les investissements publics sont affectés aux services de proximité (Grèce, Slovaquie)
- Retards substantiels dans le lancement d'appels à la désinstitutionnalisation (Slovaquie, Croatie, Tchéquie, Slovénie, Roumanie)

Recommandations nos 1 à 3

1. Organiser une formation sur l'Observation générale sur l'article 19
   - La formation devrait cibler toutes les DG
   - Elle devrait être conçue et donnée par des organisations qui promeuvent la VA et ont une expérience concrète
2. Garantir le respect de la CDPH
   - Élaborer des orientations sur la base de l'Observation générale sur l'article 19
3. Réexaminer les conditions ex ante d'un financement de l'UE après 2020
   - Exiger des stratégies globales
   - Concevoir des moyens d'évaluer les stratégies

Investissements perpétuant la ségrégation et l'isolement des personnes handicapées

Problème : les Fonds ESI continuent de soutenir des projets qui excluent les personnes handicapées de la vie dans la société au lieu de favoriser leur insertion sociale.

- Création de petits foyers de groupe sans réelle différence par rapport aux établissements dans la prise en charge (Bulgarie, Roumanie, Hongrie, Slovénie, Portugal)
- Placement d'adultes handicapés dans des familles d'accueil (Croatie)
- Absence de progrès dans la fermeture de grands établissements résidentiels (Grèce, Hongrie)

Recommandation n° 4

Prendre des mesures pour prévenir l'utilisation inappropriée des Fonds ESI :

- la CE devrait enquêter sur les cas d'« utilisation abusive » potentielle de Fonds ESI et intervenir à chaque fois qu'un projet ou un plan n'est pas conforme à l'article 19 de la CDPH ;
- elle doit faire remarquer clairement aux États membres que les Fonds ESI ne peuvent être utilisés au profit de projets qui excluent les personnes handicapées de la société ;
- elle doit collaborer avec les organisations de promotion de la vie autonome.

Procédure de suivi et de plainte inappropriée

Problème : les systèmes de suivi existants – tant dans les États membres qu'au niveau de l'UE – ne sont pas suffisamment performants pour empêcher l'utilisation de Fonds ESI au profit de projets qui perpétuent l'exclusion sociale et la ségrégation des personnes handicapées.

- Les EM doivent davantage préciser comment ils utilisent les Fonds ESI.
- Les comités de suivi jouent un rôle essentiel, mais ont besoin de soutien pour pouvoir exercer correctement leur fonction.
- Des mesures doivent être prises pour assurer que les personnes handicapées participent au suivi de l'utilisation des Fonds ESI.
- Les EM doivent bien instaurer une procédure assurant l'examen efficace des plaintes, mais la manière dont ils doivent le faire n'est pas claire.
- Les informations fournies au grand public sur le suivi des Fonds ESI sont insuffisantes et les organisations de la société civile peuvent rarement exprimer leurs réactions à la mise en œuvre concrète des projets financés par les Fonds ESI.

Recommandation n° 5

Améliorer les mécanismes de suivi des Fonds ESI :

- instaurer un système pour améliorer la procédure utilisée pour observer les investissements des Fonds ESI ;
- permettre l'accès aux informations pertinentes ;
- renforcer les possibilités pour les OSC de participer aux différentes étapes de l'utilisation des Fonds ESI.

Examiner avec une attention accrue l'impact des Fonds ESI sur la vie autonome

Problème : après qu'il a été décidé de financer un programme, une attention suffisante n'est pas consacrée à ses effets sur les bénéficiaires finaux, leur qualité de vie et leur degré d'insertion sociale et de participation à la société.

- L'implication des OSC qui promeuvent la vie autonome dans les comités de suivi devrait être sensiblement améliorée dans de nombreux EM (bons exemples en Lettonie et en Slovaquie).
- Parmi les projets prometteurs, on peut citer l'utilisation du FSE pour soutenir l'aide personnelle (p. ex. en Croatie), même si une évaluation détaillée doit être menée pour vérifier la conformité avec l'article 19 de la CDPH.
- D'autres projets qui affirment soutenir la vie autonome nécessitent également une évaluation approfondie.

Recommandation n° 6

Impliquer les personnes handicapées dans l'évaluation de l'aide qu'elles reçoivent :

- la procédure d'évaluation des projets destinés à favoriser la vie autonome doit prendre en considération l'expérience des personnes qui « bénéficient » d'un financement de Fonds ESI.

Obstacles à la réalisation d'une participation significative et manque d'informations

Problème : les personnes handicapées et leurs organisations restent largement exclues de la procédure de planification, de mise en œuvre, de suivi et d'évaluation des Fonds ESI. Peu de données attestent de l'utilisation des Fonds ESI pour faciliter la concrétisation du droit à la vie autonome.

- Exclusion des comités de suivi
- Manque de capacités
- Difficultés à accéder aux informations (Hongrie)
- Capacités juridiques et absence d'exploitation des bonnes pratiques (Roumanie)
- Exigence de cofinancement (Slovaquie)
- Appels à propositions restreints et présélection

Recommandation n° 7

Améliorer la mise en œuvre du principe de partenariat :

- la CE doit améliorer le suivi de l'engagement des OSC au niveau national ;
- elle doit étudier comment impliquer les groupes les plus marginalisés parmi les personnes handicapées ;
- elle doit encourager les EM à diffuser publiquement des informations sur les projets financés.

Poursuite des investissements de fonds nationaux dans la prise en charge institutionnelle

Problème : les EM maintiennent une prise en charge institutionnelle des personnes handicapées en construisant de nouveaux établissements de soins résidentiels bénéficiant de financements publics. Ce n'est pas considéré comme un « problème européen » bien que l'UE et tous les EM sauf un soient parties à la CDPH.

- Les investissements de fonds nationaux dans la prise en charge institutionnelle se poursuivent et l'UE ne fournit pas un soutien suffisant pour faciliter la vie autonome (Belgique, France, Allemagne, Pays-Bas, Slovénie, Espagne).
- Certains EM mettent l'accent sur la réinsertion sur le marché de l'emploi et du travail, mais les personnes handicapées peuvent malgré tout être exclues (Pays-Bas, Belgique).
- Absence de stratégies pour la désinstitutionnalisation (Allemagne, France, Belgique).
- Absence de connaissances sur l'utilisation des Fonds ESI pour soutenir la désinstitutionnalisation.

Recommandation n° 8

Inciter davantage d'États membres à utiliser les Fonds ESI en faveur de la désinstitutionnalisation :

- tous les EM qui n'ont pas encore fermé leurs établissements de soins résidentiels de longue durée pour personnes handicapées devraient inscrire la désinstitutionnalisation parmi leurs priorités d'investissements après 2020.

Aspects à traiter

1. Non-respect de la condition ex ante thématique de la **désinstitutionnalisation**
2. Investissements perpétuant **la ségrégation et l'isolement** des personnes handicapées
3. Procédures **de suivi et de plainte** inappropriées
4. Attention accordée à l'évaluation de l'**impact** des Fonds ESI sur la vie autonome
5. Obstacles à la réalisation d'une **participation significative** et **manque d'informations** sur l'utilisation des Fonds ESI
6. Poursuite des **investissements de fonds nationaux** dans la prise en charge institutionnelle

Estonie (2007-2013)

Village de Sinimäe (*Sinimäe alevik*)

Village de Sinimäe (*Sinimäe alevik*)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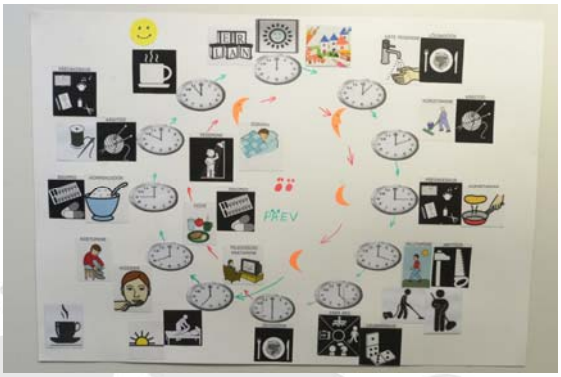

10 personnes par unité de service et 6 unités de service = 60 personnes

Planning journalier pour les clients qui habitent le foyer, qui fixe les horaires des repas, des routines quotidiennes (douche, toilette, habillage, etc.), du travail et des activités de loisirs (centre de jour, sport, artisanat, etc.)

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Règlement d'ordre intérieur du foyer (extraits)

« Je respecte le planning journalier du foyer (...) Je reste au foyer la nuit. »

« Je sais que la consommation d'alcool est interdite sur le territoire du foyer (...) »

« Si j'ai obtenu l'accord de l'ergothérapeute, je peux utiliser mes effets personnels dans ma chambre : télévision, radio, autres dispositifs techniques et meubles. »

« Si j'ai obtenu l'accord de l'ergothérapeute, je peux utiliser le téléphone du foyer 10 minutes par semaine. »

« Je suis conscient(e) que le foyer peut résilier le contrat conclu avec moi avant son expiration si j'enfreins le règlement à plusieurs reprises. »

Portugal (2014-2020)

1 – Gouvernement des Açores (http://www.azores.gov.pt/Portal/pt/entidades/srss-drss/textolmagem/ACORES-09-4842-FEDER-000010-_Construcao_do_Lar_Residencial_dos_Valados.htm)

2

3

Hongrie (2014-2020)

- Appel à propositions au titre du programme opérationnel pour le développement des ressources humaines 2.2.2 – 17. Passage des soins institutionnels aux services de proximité – Remplacement de places dans des établissements (EFOP-2.2.2 - 17) – Projets affectant 2 500 personnes handicapées et évalués à près de 24 milliards de HUF (76 millions d'euros), qui entraîneront à nouveau une ségrégation des personnes handicapées dans des centaines de nouveaux établissements de petite taille.
- L'ENIL, la Fondation Validity et l'Union hongroise pour les libertés civiles appellent le gouvernement à suspendre les projets dont la mise en œuvre a déjà commencé et à entamer une refonte en profondeur. Communiqué de presse : http://enil.eu/news/hungarian-government-must-suspend-redesign-deinstitutionalisation-projects-affecting-2500-people-disabilities/

• Problèmes constatés :

- Bon nombre des foyers collectifs qu'il est prévu de construire seront situés à distance des villes, dans des milieux ruraux à faible densité de population, suscitant un plus grand ostracisme encore pour les personnes handicapées. Dans de nombreux sites choisis pour leur implantation, les services publics font défaut, les communautés sont vieillissantes et la population est en déclin.
- Certains foyers collectifs doivent être construits sur des terrains inondables, dans des zones industrielles inaccessibles, dans des zones marécageuses couvertes de roseaux ou près d'une installation d'évacuation des eaux d'égout.
- Souvent, les foyers collectifs doivent être construits sur la propriété de grands établissements actuels ou dans leurs environs immédiats. Les résidents seront emmenés en minibus dans ces nouveaux foyers, appelés Centres de services, qui seront fréquemment installés dans le périmètre, ou parfois même à l'intérieur des anciens grands établissements. Les personnes handicapées seront toujours prises en charge comme par le passé, dans un milieu institutionnel, y compris pour leurs repas.
- Les nouveaux foyers résidentiels fonctionneront à la manière d'établissements de soins miniatures, dans lesquels les personnes handicapées seront privées de leur indépendance et ne pourront pas décider où et avec qui elles vivent, choisir un métier ou adopter leur propre routine quotidienne.

Ressources utiles

- ENIL – Instructions sur l'utilisation des fonds de l'UE pour une vie autonome (en anglais seulement) : http://enil.eu/wp-content/uploads/2018/04/EU-Funds-Briefing_web0903.pdf
- Instructions de l'ENIL – Pour un système de suivi et de plainte plus efficace (en anglais seulement) : http://enil.eu/wp-content/uploads/2017/07/OurRightsCampaign-Briefing_FINAL.pdf
- Rapport de l'ENIL – Réduire ensemble l'écart entre les droits et la réalité (en anglais seulement) : http://enil.eu/wp-content/uploads/2016/06/Working-Together-to-Close-the-Gap.pdf
- Instructions de l'ENIL sur les investissements des Fonds structurels pour les personnes handicapées : passer de la prise en charge institutionnelle à la vie dans la société (en anglais seulement) : http://community-living.info/wp-content/uploads/2014/02/Structural-Fund-Briefing-final-WEB.pdf
- ENIL – Idées fausses sur la vie autonome (en anglais seulement) : http://www.enil.eu/wp-content/uploads/2014/12/Myths-Buster-final-spread-A3-WEB.pdf
- Observation générale sur l'article 19 de la CDPH : https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=fr

- Règlement portant dispositions communes (RPDC) : http://eur-lex.europa.eu/legal-content/FR/TXT/?uri=CELEX:32013R1303
- Règlement relatif au FEDER : https://eur-lex.europa.eu/legal-content/FR/TXT/?uri=CELEX%3A32013R1301
- Règlement relatif au FSE : https://eur-lex.europa.eu/legal-content/fr/TXT/?uri=CELEX%3A32013R1304
- Portail des données ouvertes – DG Regio (en anglais seulement) : https://cohesiondata.ec.europa.eu/
- Orientations relatives à la garantie du respect de la charte des droits fondamentaux de l'Union européenne lors de la mise en œuvre des Fonds structurels et d'investissement européens (« Fonds ESI ») : http://eur-lex.europa.eu/legal-content/FR/TXT/?uri=uriserv:OJ.C_.2016.269.01.0001.01.FRA&toc=OJ:C:2016:269:TOC
- Règlement délégué (UE) nº 240/2014 de la Commission du 7 janvier 2014 relatif au code de conduite européen sur le partenariat dans le cadre des Fonds structurels et d'investissement européens : http://eur-lex.europa.eu/legal-content/FR/TXT/?uri=uriserv:OJ.L_.2014.074.01.0001.01.FRA
- Le FSE dans votre pays : http://ec.europa.eu/esf/main.jsp?catId=45&langId=fr
- FEDER : http://ec.europa.eu/regional_policy/fr/atlas/managing-authorities/
- Orientations sur les Fonds ESI : http://ec.europa.eu/regional_policy/fr/information/legislation/guidance/
- Accords de partenariat (en anglais seulement) : https://ec.europa.eu/info/publications/partnership-agreements-european-structural-and-investment-funds_en

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Case study

Country A
Within its DI strategy, Country A decides to create community based services for people with disabilities. Country will use 60 mil EUR to move people from institution. Plan is to move people in different areas around the country, some of them are in rural zones, some in industrial zones. Many houses will be very close to former institutions. People will be living in small houses and they will be transported to service centres. Some of service centres are placed in former institutions and some in the area near former institution.

Roles:
European Commission – What would you check within this project and would you finance it? What is good/bad in this project?
European Ombudsman – How would you see this project and what do you think it is good/bad in it?
DPO – What would you do?

Country B
Country B is an island and has just built a new place for people with disabilities. It is next to the beach. 16 people will be placed there.

Roles:
European Commission - What would you check within this project and would you finance it? What is good/bad in this project?
European Ombudsman – How would you see this project and what do you think it is good/bad in it?
DPO – What would you do?